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## **Cancer Care Coordinators: Realising the Potential for Improving the Patient Journey**

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A person diagnosed with cancer can receive multiple treatments in a variety of different health care settings over extended periods of time<sup>1</sup>. During this time, they come into contact with multiple health care providers. For example, one recent UK study reported that cancer patients with a diagnosis of less than one year had met 28 doctors on average since their diagnosis<sup>2</sup>. Add to this the many other health professionals with whom the patient will come into contact during their illness and the complex maze that can characterise the patient's cancer journey is obvious.

The Optimising Cancer Care in Australia report<sup>3</sup> published in 2003 by the peak cancer organisations in Australia concluded that there are many places for the person with cancer to get lost in the system, causing unnecessary morbidity and undue distress. The lack of an integrated care system for people with cancer was identified as a major failing of today's health system<sup>3</sup>. A number of states in Australia have moved to appoint cancer care coordinators as a strategy to address such problems. In Queensland, cancer coordination positions have been established in a number of Health Service Districts in the Southern and Central Zone of the State, initially to scope patterns of care, referral pathways and to define a cancer coordination model for their regions that is consistent across the state, but able to meet the local needs of the population. To support its Cancer Clinical Service Framework, the NSW Health Department plans to recruit up to 50 cancer nurse coordinators. Cancer nurse coordinators in NSW will work through Lead Clinicians and Directors of Area Cancer Services to support oncology team meetings, develop care pathways and protocols, and provide a direct source of contact for patients and primary care physicians accessing cancer services<sup>4</sup>. In Victoria, a number of program coordinators and regional nurse coordinators have been introduced as part of the breast services enhancement program. Individual institutions have also established nurse coordinator roles for specific tumour streams.

The cancer care coordinator role is a rapidly emerging one with a mandate 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 system.

### **What is Care Coordination?**

A variety of terms are used in the health care literature to reflect efforts to improve the patient journey, including continuum of care, coordination of care, discharge planning, case management, integration of services and seamless care<sup>5</sup>. In the context of managing a chronic disease such as cancer, continuity of care has been defined as the delivery of services by different providers in a coherent, logical and timely fashion, consistent with the patient's medical needs and personal context<sup>5</sup>. A service system that facilitates continuity of care is characterised as one where all services needed (comprehensiveness) are delivered over time (longitudinally) by service providers who establish secure and dependable relationships (relationships) and when appropriate care is available (accessibility) and flexible enough (responsiveness) to meet patient needs<sup>6</sup>.

These definitions emphasise that care coordination is an integral component of continuity of care. Care coordination ensures that someone manages the care process, including the development and communication of the care plan and ensures that all of the care needed is arranged and delivered<sup>6</sup>. Various models for care coordination have been described to reflect the needs of the population being served. Case management is one such example that evolved from efforts to decrease fragmentation of services for patients whose care was complicated, being seen as a cost-effective way to provide quality care to high-risk patient groups and improve selected patient outcomes<sup>7</sup>. While no agreed definition is evident in the literature, nurse case management roles are generally seen to encompass a very broad range of responsibilities which may include assessment and screening of needs and goals, education, bridging gaps, promoting self efficacy, enhancing self-care capabilities, coordinating care across settings, brokering and developing networks of services, advocating for patients and providing hands on care<sup>8,9</sup>. The development of standardised care protocols, such as care maps, pathways and guidelines have also been identified as an important mechanism for achieving coordinated and continuous care<sup>6</sup>.

While coordination of care, case management and care pathways are processes designed to promote continuity, on their own, they do not necessarily ensure that a patient experiences a system that is connected and coherent<sup>5</sup>. Studies suggest that patients and their families experience continuity when they perceive that providers know what has happened before, that different providers agree on a management plan, and that a provider who knows them will care for them in the future<sup>6</sup>. Such studies emphasise that what is likely to be highly valued by patients is not simply a managed care process, but rather, a relationship with a clinician that is characterised by understanding, trust and mutual respect<sup>10</sup>.

Care coordination may therefore be most effective when it achieves continuity across several interrelated dimensions of the patient's cancer experience, including:

- Informational continuity, or the efficient transfer of information about the patient's disease as well as their preferences, values and context in order to bridge separate care events and ensure a responsive service<sup>5</sup>;
- Management continuity, or the delivery of services in a complementary and timely manner that are consistent and flexible<sup>5</sup>;
- Relational/interpersonal continuity, or the linkage that is made between past to current and future experiences<sup>5,11</sup>; and Team continuity, or the extent to which care is delivered within a shared management plan<sup>5,11</sup>.

These dimensions emphasise that the experience of a connected and coherent service is intricately linked to organisational, interpersonal and relational aspects of the health system.

### **What is the Evidence for Care Coordination?**

Two major reviews of evidence regarding coordination of cancer care were published in 2003. The National Institute of Clinical Excellence in the UK undertook a systematic review of literature published between 1966 and March 2003 to determine the current state of evidence on interventions to improve service configurations for supportive and palliative care for those affected by cancer<sup>12</sup>. In the area of coordination of care, 13 individual studies were identified which had evaluated interventions including appointment of nurse coordinators, multidisciplinary team interventions, introduction of standardised guidelines and protocols and implementation of methods for improving communication, such as patient held records. The reviewers concluded that the evidence shows good coordination enables services to complement each other and provide better quality supportive care services. Of particular note, however, is that 11 of the 13 studies identified in this review involved coordination of services for patients receiving palliative care.

The Clinical Practice Guidelines for Psychosocial Care for Adults with Cancer<sup>1</sup> published in Australia similarly discusses evidence around four main types of interventions designed to promote continuity of care: identification of a care coordinator; the role of specialist oncology nurses; multidisciplinary care; and patient held records. The review concluded that Level 2 evidence exists to support the following interventions: ■ Specialist breast nurses improve understanding and provide continuity of care throughout the treatment process for women with breast cancer; and ■ Patient held records improve continuity of care.

While care coordination is not the sole focus of the Specialist Breast Nurses' practice, the establishment of such positions in Australia has represented an important development in efforts to improve coordination and support for women with breast cancer. The National Breast Cancer Centre (NBCC) Specialist Breast Nurse Project identified that the presence of a specialist breast nurse contributed to a range of improvements including: improved team functioning and appropriate utilisation of each professional's skills and resources; care being delivered more smoothly, including referrals; other health professionals having improved information about patients and breast cancer issues; and women being prepared for each treatment stage<sup>13</sup>. The recent report on the NBCC Multidisciplinary Care Demonstration projects reinforced this important role that specialist oncology nurses

play as a coordinator of care and facilitator of effective communication amongst the team and with patients<sup>14</sup>.

Further evidence to support the role of nurse coordinators in improving outcomes for people with cancer has emerged since the publication of these evidence reviews. A US based study by Goodwin et al<sup>15</sup> evaluated a nurse case management intervention in a randomised controlled trial involving 335 women over 65 years of age newly diagnosed with breast cancer. Findings demonstrated that women who received the support of a nurse case manager were more likely to be seen by a radiation oncologist and receive radiotherapy after breast conserving surgery and that they were more likely to have normal arm functioning in the recovery period than women who did not receive case management support. Similarly, a three year demonstration project in the US involving patients with advanced lung cancer found that where nurse case managers were employed, higher rates of advance care planning and referral to hospice programs and improved symptom management was achieved<sup>16</sup>.

The available evidence thus suggests that the appointment of someone to coordinate care may have many benefits for patients and the team. The actual processes of care that contribute to improved patient outcomes are, however, not always clearly described. That is, exactly what is it that nurse case managers or care coordinators do that makes a difference? Findings from a qualitative study involving those women with cancer who received a nurse case management intervention identified that patients felt they had been helped through practices including managing co-existing problems, providing informational and emotional support, providing education about procedures and self-care, and assisting with activities of daily living<sup>17</sup>. Navigating the health system was also a key part of the case management intervention that was seen by women as being especially helpful and this included making appointments, explaining procedures, reinforcing information from other health care providers and ensuring comprehensive recording of patient information in health records<sup>17</sup>. Families of patients in this study reported the nurse case managers helped by providing advocacy, support, education and monitoring of their relative's progress<sup>17</sup>.

Similarly, findings from a qualitative study of the practices of nurse case managers working in a state-wide program in California for uninsured men with prostate or bladder cancer identified that nurse case manager's scope of practice was extremely broad and required 'skilful tailoring and execution' of a range of interventions including:

- assessment and collection of data from a variety of sources to identify patient needs;
- synthesis of this assessment data with their own clinical expertise and understanding of the clinical, social and emotional context for the individual patient;
- use of facilitation strategies to promote successful self-action and expedite movement within the health care system;
- advocacy strategies including obtaining records or information that patients needed and representing patient needs and preferences;

- coordination strategies to link agencies, care providers and patients, such as coordinating appointments, obtaining records, completing paper work, making referrals and arranging supplies;
- teaching to fill gaps in information or understanding;
- support through reassuring, listening and supporting decisions; and
- collaborative problem solving through active listening, purposeful questioning, elicitation of preferences, identifying actions and reinforcing capabilities<sup>4</sup>.

### **What Issues Should be Considered in Implementing Care Coordination Roles?**

Published studies concerning care coordination interventions have typically involved evaluation of quite structured programs of nurse intervention, with participating nurses being well supported and educated to perform in their roles. In reality, however, coordination roles are more likely to be implemented in diverse contexts with varying levels of structure, guidance and support. As such, outcomes for patients and for the system have the potential to be far more varied than evidence from the more controlled evaluation studies might suggest. For example, a comprehensive descriptive study of the practices of 153 breast care nurses in Victoria found that the breast care nurse role in working with and involving other health professionals in women's care was varied, that joint consultations with other health professionals were not always a routine part of practice and that referral rates by all breast care nurses to some professional groups was limited<sup>18</sup>. Indeed, despite a belief that continuity of care interventions are inherently good, some studies of coordination interventions outside of the cancer context (mostly in primary care settings) have reported conflicting conclusions as to their value<sup>19</sup>. There are likely to be many reasons for such variations in practice and outcomes, including inadequate preparation of care coordinators and other members of the team, poorly designed interventions, or simply lack of access to appropriate services and systems of support to enable collaborative practices to occur.

The findings from the Victorian Breast Nurse Workforce study are an important reminder that while care coordinator roles may have enormous potential, careful consideration needs to be given to how such roles are designed and implemented. The brief review presented in this paper raises some important questions for further consideration.

### **What is the Scope of Practice and Associated Competency Requirements for a Cancer Care Coordinator?**

Qualitative studies describing the practices which contribute to patient's experience of a coordinated system identify an enormous array of administrative, counselling, educational, advocacy and clinical functions that may be performed by nurses in care coordination roles. There is, however, no consistent definition of the scope of practice, or clear description of the capabilities and competencies required to be an effective cancer care coordinator. For example, to what extent should such roles focus on management and coordination of the various parts of the service system (eg. a type of case management or systems navigator role), more direct care provision in terms of meeting individual patient supportive care needs (eg. counselling and education, such as

provided by the Specialist Breast Care Nurse), or a combination of these functions? Inherent in this is the question of how the care coordinator's role differs to or complements the role of other cancer specialists such as that of breast care nurses. A prescriptive model of care coordination is, of course, unlikely to meet the diverse needs of people with cancer. Nevertheless, addressing key questions about role definition will be crucial for developing evidence-based models of care coordination that are appropriate for the populations being served. Such clarity will also assist consumers and other health professionals to better understand their relationship with care coordinators, as well as minimise role confusion and the perception that care coordinators can be 'all things to all people'.

### **When is Care Coordination Required, To Whom and Under What Circumstances?**

In the cancer context, the specific patient circumstances that will benefit most from support provided by care coordinators are yet to be clearly identified. Studies that have evaluated case management interventions have tended to involve patients with complex health or social needs<sup>15,16,20</sup>. In the primary care context, studies similarly suggest that continuity of care interventions are associated with more positive outcomes for more vulnerable patients<sup>21</sup>. Furthermore, while studies demonstrate the potential benefits of care coordination interventions in both the treatment phase<sup>15</sup> as well as palliative phase of illness<sup>16</sup>, the best timing and length for care coordination interventions is not well defined. Few studies have reported on coordination activities in post-treatment or follow up stages of the patient's journey.

### **A host of questions arise when considering issues regarding delivery and timing of coordination interventions. For example:**

Do all patients require services provided by a care coordinator? What is an appropriate casemix and caseload for care coordinators? Should the cancer nurse coordinator work within one institution, a primary care setting, or work between several organisations? It is likely that the multitude of pathways that a person with cancer may follow, combined with the unique features of Australia's geography and population distribution, will mean that there is no one answer to these questions. Nevertheless, ensuring equity of access and appropriate use of resources will remain critical policy considerations. Who Can Best Fulfil the Role of Cancer Care Coordinator? The majority of evidence relating to the coordination of cancer care has involved the use of nurses as case managers or in structured support roles, such as that of the specialist breast nurse. The Clinical Practice Guidelines for Psychosocial Care for people with cancer identified that specialist oncology nurses, in both inpatient and outpatient settings, play a major role in ensuring continuity of care by coordinating the patient's path through treatment, liaising with different members of the team, and monitoring the person with cancer<sup>1</sup>. The guidelines also suggest that GPs can be useful in ensuring continuity of care as they have knowledge of patient's social and medical background, especially in relation to follow up and management of co-morbid conditions<sup>1</sup>. There are, however, few studies in the cancer context to assess the interest, abilities or capacity of GPs to perform these roles. Other health professionals, such as social workers may also play an important role in care

coordination<sup>22</sup>. It is possible that different disciplines will have different coordination roles at different times of the patient journey and moreover, that all health professionals have some role in ensuring continuity of care. Indeed, the Psychosocial Clinical Practice Guidelines recommends that the patient should be given a choice as to whom they wish to be the coordinator of their care. At the very least, the key question that should drive decisions about who is best placed to act as a care coordinator is: What are the support and coordination needs of patients in this context?

### **How Does the Care Coordinator's Practice Interface with that of Other Health Professionals?**

Perhaps the most challenging feature of care coordination interventions is the interface between the functions of an appointed care coordinator and those of other members of the health team. A review of the type of activities that are suggested to be within the scope of practice for care coordinators highlights the potential for role overlap, role conflict, and duplicated and fragmented efforts. Despite these concerns, the NBCC Specialist Breast Nurse Project found that while some practitioners initially expressed concern that the specialist breast nurse role may corrode other professional's role, or provide confusing or conflicting information, such concerns were unfounded and where role overlap did occur, this was resolved or used to advantage<sup>13</sup>. For care coordination roles to be effective and efficient, high quality communication and considerable flexibility will need to be practised as various members of the health team negotiate blurred and changing practice boundaries. The relationships between care coordinators and other specialist cancer nurses will require especially careful negotiation in day-to-day practice. Conclusions The high priority currently being given to developing a more coordinated care system represents an important shift towards a person-centred approach to cancer care. The strategies required for achieving such improvements are multifaceted and are likely to involve developments in multidisciplinary care, improved communication systems and, as this review suggests, the identification of personnel whose core business it is to facilitate as smooth a journey as possible for patients. The available evidence suggests that the appointment of care coordinators has the potential for improving the patient's cancer experience. Importantly, however, the success of care coordination roles will depend on further development of appropriate systems of support and interdisciplinary approaches to care. The development of evidence-based frameworks that clarify scope of practice, competency standards and related training requirements for care coordinators also remains a priority.

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