

The role of the cancer nurse coordinator: an observational reflective study

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Abstract

Introduction

Cancer is a complex, multifaceted condition requiring multimodal treatments over prolonged periods of time, in a variety of settings, delivered by multiple health professionals. Patients have reported confusion and fragmentation with their care and in many centres, cancer care coordinators (CCCs) have been employed to solve this problem.

Method

A convenience sample of CCCs were observed over a period of one week to understand and interpret how they apply their role in the clinical setting to meet the needs of their patients and clients.

Results

Three key prominent themes were observed in the role of the CCC: general assessment; psychological support; and educational support. Coordination of care and of the multidisciplinary team was not observed as a prominent role in the sample observed.

Conclusion

CCCs assess, educate and support the patient and their family during treatment with an aim of holistic care.

Keywords: Cancer, care coordination, multidisciplinary, nurse care coordinator.

Introduction

The lack of an integrated care system for the cancer patient was highlighted in the *Optimising Cancer Care in Australia* report¹, which concluded that many patients can become lost in the system. This contributes to patients experiencing unnecessary morbidity, confusion and undue stress. Patients entering the health system require a coordinated response that is focused on improving the patient journey¹. In Australia, the role of the cancer care coordinator (CCC) was developed, partly as a result of the overwhelming evidence that cancer care is an increasing burden on the health care system, but mostly to improve patient outcomes¹². Increased satisfaction and decreased anxiety, particularly in the early stages of diagnosis, has been reported as outcomes that impact the patient. When patients are less anxious and better informed they are more likely to discuss and consider treatment options, participating actively in decision-making processes³.

To assist cancer patients as they navigate the health care system the term care coordination has emerged⁴. Care coordination is referred to by many different terms, including continuity of care, seamless care, case management, integration of services and discharge planning^{2,5-7}. Nutt and Hungerford sought to define nurse care coordinators as an advanced practice nurse who engages directly with a patient; manages the overall care process, including the development and communication of the care plan to all relevant stakeholders; and ensures that all treatment and care is delivered to meet the specific needs of the patient and his/her significant other(s)⁷. The Cancer Nurses Society of Australia (CNSA) position statement on cancer care coordination defines a CCC 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"⁸.

As background preparation for this study, an extensive review of pertinent literature between 2000 and 2013 was undertaken using Pubmed and CINAHL using keywords: "cancer care coordinator", "patient navigator", "clinical care coordinator". Two major themes emerged from the literature: development of cancer care coordination and the role of the CCC.

Background

Development of cancer care coordination

Cancer treatments and ongoing care are complex and often confusing, with reports of patients and families feeling lost in the system²⁹. The literature suggests that Australian cancer care delivery is fragmented due to the many different services and providers who are responsible for screening, diagnosis, treatment and supporting care². This can result in suboptimal communication between providers and patients, leading to unmet needs during the provision of care².

International research shows that this fragmented care experience is not unique to Australia. In the 1990s the first patient navigation program was established at Harlem Hospital in New York¹⁰. The program was an attempt to overcome the barriers such as poverty, culture and social injustice, improving health outcomes for cancer patients in a predominately poor community and of African-American and Hispanic heritage. Patient navigation aimed to reduce barriers to care and enable persons with cancer-associated symptoms to receive timely diagnosis and treatment¹⁰⁻¹⁵. In the United States the commonly recognised barriers to timely care were financial, communication, information, and emotional factors, as well as the medical system itself⁵. The benefit of a patient navigation program in Harlem was illustrated in the five-year survival rates of predominately black women of a low socio-economic background diagnosed with breast cancer. In 1986, 49% of the women diagnosed had stage 3 and 4 disease with a five-year survival rate of only 39%. By 2000, after implementation of the program, 41% of the women diagnosed had early breast cancer and only 21% had stage 3 and 4 disease, and the five-year survival rate had risen to 70%^{33,15}.

In the United Kingdom the Calman-Hine Report was published in 1995 by an Expert Advisory Group on Cancer, who then released a plan that outlined radical reforms for Cancer Services¹⁶. The aim was to improve outcomes and reduce the inequalities in cancer care within the National Health Service (NHS). Subsequently the Improving Outcomes Guidance (IOG) reports and the NHS Cancer Plan 2000 combined to make recommendations that cancer care should be arranged by site specialists, including the specialist cancer nurse working together in multidisciplinary cancer teams¹⁶.

A review of the role

McDonald *et al.*¹⁷, conducted a review of the literature in 2006 in an attempt to develop a working definition of the navigator (coordinator) role in the USA. More than 40 definitions of care coordination were identified, from which they formed their inclusion and exclusion criteria. From 4,730 publications identified, 75 were included identifying 20 different coordination interventions. Care coordination is a dedicated role and the CCC could be a nurse, social worker or other allied health professional or a general practitioner, or, as it is in the United States, even a lay person. Freeman's role description of the patient navigator (coordinator) is to ensure that the patient receives timely diagnosis and treatment, through one-on-one contact and to eliminate the barriers to achieve this¹³. Freeman discusses that the patient navigator is not required to have a particular level of education but should have other qualities, such as being culturally attuned, well connected with the decision makers within the system and knowledgeable about the system to enable them to assist the patient as they navigate a complex health system¹³.

In the United Kingdom, in the report *The Improving Outcomes: A Strategy for Cancer*, it is acknowledged that coordinated care, such as that provided by clinical nurse specialists, can deliver better outcomes for patients¹⁸. The benefit of one-to-one support was found to achieve a service that outweighed the cost. MacMillan Cancer Support, one of the largest British charities providing specialist health care, information and financial support to people affected by cancer, supported the NHS to create almost 3,000 additional clinical nurse specialist and care coordinator positions, and the UK has recognised that nurses are ideally placed to fulfil these roles¹⁸.

The Australian government recognises that cancer patients report suboptimal experiences as they traverse the medical system, navigating multimodal and specialist care, describing it as being not dissimilar to "a train trip across Australia"¹⁹. A range of health professionals provide cancer care across multiple health services and across health sectors, including public, private and community in both metropolitan and rural areas. Thus, patients must move between the services and there are many opportunities for delays and for patients to become lost in the system²⁰.

Yates describes care coordination as "enhancing the patient's experience during illness through providing continuity of care across several interconnecting components of cancer care"¹⁴. It can be said then that cancer care coordination aims to provide a service that occurs logically and in a timely fashion, consistent with the needs of the patient and in context of the medical care

required⁴⁷. The activities of CCCs were explored by Walsh *et al.* in a qualitative research study of 29 Australian clinicians involved in cancer care²¹. Some of the major components identified were: a needs assessment and organisation of care; patient access and navigation of the health system; as well as being the person who ensures effective communication and cooperation between health professionals. In the report from the Clinical Oncological Society of Australia (COSA) 2006 CCCs workshop, Yates identified that key roles of the CCCs are centred on providing continuity of care, enhancing the experience and minimising further distress of the patient diagnosed with cancer².

Using strong consumer input, the *Optimising Cancer Care in Australia* report¹ recommended patient-focused, coordinated, multidisciplinary care, an end to the cancer care "referral lottery", reasonable access to evidence-based quality care, including clinical trials, and support throughout the cancer journey²².

The following study explores the role of the CCC in a metropolitan hospital in South Eastern Queensland. The research question was "What are the key activities of the CCC in the Australian hospital environment?"

Method

This observational study used reflection to understand the role of the CCC. Observation and reflection provided an insight into the role across different tumour streams. A convenience sample of three CCCs responsible for different tumour streams from the same hospital was enlisted into the study to explore the similarities and differences in approach to the same role. Guided by the principles of descriptive ethnography, the researcher collected data by observation and discussion with each CCC²³. The researcher explored the roles of the CCC by following them closely as they undertook their daily activities. Notes were taken and then analysed for themes around the roles and interactions of the CCC. Reflection was used to gain meaning from the interactions as the researcher continued to observe each CCC in their natural setting.

The study was completed for student learning purposes only and was internally assessed by the local institutional guidelines and designated as negligible risk²⁴. Verbal consent was obtained from the CCCs and ethical principles maintained as per ethical guidelines for work which is exempt from full ethical review²⁵. The study was reported to the ward as part of development of roles.

Reflection as a means of exploration and understanding

Reflective practice is a means for empowering the health professional to learn from and build upon clinical experiences and involves purposeful thinking about an experience with

the goal of gaining new insights, ideas and understanding²⁶. Reflective practice can also "involve looking at the power relations that exist in the health care environment and asking questions about how and why they exist and whose interests are served by their existence"²⁷. To reflect is not enough; the knowledge and new understanding must inform practice. Gibbs²⁸ model of reflection is frequently used within nursing; it is clear and precise, allowing for description, analysis and evaluation of the experience, assisting the reflective practitioner to make sense of the experience.

Sample

Two clinical nurse consultants (CNCs) and one clinical nurse (CN) were observed for one week in their role of care coordination within the breast, colorectal and hepatobiliary tumour streams. Observations included the CCC in multidisciplinary team (MDT) meetings, surgical and oncology medical clinical appointments, performing data input and attending telephone consultations.

Results

The results are presented in three themes: general assessment; psychological support; and educational support.

General assessment

The CCCs discussed the difficulty of meeting patients personally to assess them at the time of diagnosis. Assessments were conducted in a variety of settings and differing times throughout the patient journey. The first observation was at an initial discussion of the patient at a colorectal MDT meeting. The medical team were concentrating on their individual treatment for the patient. The CNC was able to provide a holistic, detailed presentation of the patient, not just the medical components that each consultant presented to support their preference for particular treatment. This patient was elderly and legally blind and would have had difficulty managing the result of the planned surgery. The patient had already expressed their wishes to the CNC as to what would be acceptable and would not be acceptable when the CNC had met with them to support the decision-making process. This enabled the treatment plan to be inclusive of the patient's needs and preferences, demonstrating patient advocacy.

In a busy surgical review clinic the colorectal CNC had identified that she had several patients that she felt were imperative to assess. The CNC went between clinic rooms quickly, sitting in on discussions with three different consultant surgeons. She made quick observational assessments, listening to the conversation, probing where necessary and involving any other family members for further information. There was a sense of hurriedness without rush as the CNC attempted to see as many patients as possible,

including those that presented with new issues. The advanced skills of the CNC were evident when assessing the physiological processes and symptom management of patients in this setting. The CNC reviewed patients across different diseases, stages and treatment modalities, gathering patient details and specific needs, with an aim to provide holistic care. It was a challenging environment and time management was paramount. The CNC was able to prioritise patients and managed time efficiently, between busy colorectal and hepatobiliary clinics.

Psychological support

In all tumour streams the CCCs discussed emotional support as being an activity that is most vital yet the most time-consuming of the role. Each new patient completes a psychological screening tool, to assess risk factors that may require referral for further psychological support. Those who are identified *at risk* are prioritised and seen by the CCCs. These patients initially may require significant time and advanced assessment and communication skills. When this occurs it prevents the CCC from seeing all the new patients. This was identified as a major barrier to the CCCs having an initial face-to-face assessment with other newly diagnosed patients. This was evident when observing the breast CN in a busy medical oncology clinic. Observing the CN meet a newly diagnosed patient and her partner who had identified as *at risk* with the psychological screening tool illustrated how advanced communication and assessment skills are integral to the role. The CN experienced some difficulty with the interview and time spent with this couple was significant. A psychologist could have been contacted for support, though the CN did not offer or seek their input. The CN did document and discuss the patient with their CNC and the patient was followed up the following day. In comparison, the breast CNC was observed performing an initial assessment with a newly diagnosed patient. Using the assessment tool, the patient was identified as at high risk of depression and the CNC quickly developed a rapport, agreed on a plan of care, offering referral to the psychologist and providing a point of reference for any future interventions.

The CCCs are acutely aware that this assessment and appropriate referrals are important to achieving optimal outcomes. Reflecting on how the CNC probed gently and sensitively revealed the extent of maturity required for the CCC to provide emotional support in this context. The CNC was not intrusive or counselling, but instead listened and empathetically supported the patient, validating her stressors and offering strategies to support her. In summary, the role of the CCC was to undertake physical, emotional and psychosocial assessments, providing appropriate referrals and strategies to support patients and their

families at initial contact and throughout the entire journey. The use of a screening tool was helpful and provided the CCC with a means to identify at-risk patients efficiently and to prioritise their time effectively.

Educational support

While providing education to a new patient in the medical oncology breast clinic, the CNS clarified the patient's level of understanding, diagnosis and planned treatment through very focused questions and considered the information required. Reflecting on the CCC's educational role, the CNS structured the session so it felt like information sharing rather than educating. In contrast, the CN when observed appeared to follow a formula or 'script' when providing education to the new patient, which became instructive. The CNS identified those questions the patient wanted to have answered, answering them, looking for understanding and then offered the patient further support with phone calls and clinic appointments.

The ability of the CCC to continue contact throughout the patient journey allows them to build on the information learned and ultimately understanding. Observing how the education is delivered by the CCCs it was evident that the experienced CCC had a patient-centred and flexible approach to the education process and processed superior communication and engagement strategies. Education was appropriately paced, ensuring that the information was checked, retained and relevant to each phase. In summary, the CCC education support role is to provide education, clarify patient understanding, build on that and again review for patient retention.

Discussion

This observational study has provided insights into the practice of a small sample of CCCs working in one facility. One of the main findings is recognising that cancer care coordination needs to provide the patient with holistic care within the medical model. The *Optimising Cancer Care in Australia* report identifies that there must be an integrated, multidisciplinary, patient-focused health system throughout the cancer journey to ensure best practice¹.

The specialised cancer nurse has the skills to perform patient assessment and provide appropriate interventions. In this study, the CNCs are advanced clinical nurses with postgraduate qualifications providing them with advanced clinical skills to understand the physical impact of cancer and treatment modality side effects. The advanced clinical nurse is able to provide the patient with knowledge and understanding of their disease, helping to decrease the anxieties that they may experience, empowering the patient and giving them control

to focus on adhering to their treatment and getting well²⁹. This study identifies that the CCC requires advanced knowledge of and experience in treating the complexity of patients with cancer. The CCC forms a pivotal role in performing assessments to guide care planning and follow-up, particularly because many caregivers and patients do not communicate their concerns clearly to the clinicians. Literature identifies that many patients and caregivers believe that pain, grief, anger, and suffering are inevitable with cancer and fail to discuss their distress with health professionals³⁰.

This study identified that the CNC confidently picked up the cues from the patient and family in regard to requiring emotional support, completed a psychological assessment, and provided support and ongoing referrals. The CCC collaborates with all members of the MDT, facilitating the provision of physical and emotional support to patients and families including therapeutic conversations and supportive strategies³¹. The CCCs in this study demonstrated that they were an essential part of the team, finding time to assess, implement and coordinate care throughout the patient's journey. Although coordination of care was not observed during the study, this was described as arranging referrals to other health professionals, assisting with transportation issues, and guiding patients through the health services of other hospitals.

Willig³² describes in her phenomenological study exploring the discourse of cancer, highlighting how a patient's needs change as their understanding of cancer changes. The evidence suggests that patients are rarely given 'space' with the medical consultations to ask questions and express any fears, resulting in a lack of emotional issues being investigated in such crucial times³³. The current study identified that the CCC played an important role in understanding and addressing physical and psychosocial needs of the patient.

Improving education for cancer patients has become recognised as part of the professional role of nurses³⁴. Patient education is described as ascertaining existing knowledge, providing information and instructions for self-management, clarifying and reinforcing information, while ensuring individual needs are met³¹. Sensitive communication with patients may challenge nurses in the clinical care setting where time and understanding of how to open the conversation is paramount^{33,35}. When oncology nurses do not have strong communication skills, the nurse's communication with patients and families are often at a superficial and non-therapeutic level, failing to meet the patient's needs^{34,36}. In this study, the CCCs undertook education at every interaction through questioning and feedback, tailoring and triaging their available resources to each patient. Different

skills were demonstrated by the CCCs depending upon their level of experience; however, they sought to provide education that ensured the patient and family were given many opportunities to ask questions throughout their treatment and beyond.

This observation and reflection allowed a window into the complex roles of the CCC. Cancer care coordination is undertaken differently among the nurses within this service, potentially due to the specific requirements of each tumour stream, although this may also reflect personal preferences and non-preferences also. All of the CCCs in this study acknowledged that the needs of each patient differ greatly in terms of the organisation of their care, and attempting to predict those that require more interventions was important, particularly when clinic times and the balancing of several teams impacted on their ability to screen effectively. Some of the most challenging times for all of the CCCs were the interactions between the other members of the health team, where role overlap, duplication and role conflict were identified^{10,29}.

Similarly, Yates acknowledges that the most challenging feature of care coordination is the interface between the functions of an appointed care coordinator and those of other members of the health team⁴. Evaluating the role is integral to demonstrate the need for an experienced oncology nurse as the care coordinator. In her report on the Clinical Oncological Society of Australia Cancer Care Coordinators workshop in 2006, Yates identified "team views of their functioning" and "patient views of their experience" as two strategies that may enable demonstration of outcomes of the role of CCCs⁴. Opportunities for evaluation may include patient satisfaction surveys, quality improvement initiatives, demonstrating cost-effectiveness and decreased hospitalisations due to treatment complications²⁹.

The 2010 COSA Care Coordination Conference, *Relationship, Roles, Reality*, highlighted the central role of the CCC within the MDT and that care coordination was the responsibility of the entire team rather than one individual³⁷. Similarly a study by Regan *et al.*³¹ concluded that the CCC was "everything to everyone"³¹.

In this reflective study, the importance of several key roles of the CCC has been identified, those being needs assessment²¹; enhancing the experience; and minimising further distress of the patient diagnosed with cancer⁹; support throughout the cancer journey²²; and, in particular, the psychological support services^{38,39}.

Limitations

This study is limited by the small number of participants; however, the observational data does provide an insight into the

CCC role. This is an area of research where larger, more robust studies are needed.

Conclusion

The role of the CCC can be described as a central point of contact for the patient and their caregivers and integral to the promotion of continuity of care. CCCs assess, provide emotional support, and educate the patient and their family during their cancer treatment journey with an aim of holistic care. Further research understanding the complexities of the role and demonstrating measurable patient outcomes is important in looking to the future of an integrated, multidisciplinary, patient-focused health system. In addition, the development of a framework for continuing professional development, mentoring and clinical practice will provide guidance to and support for nurses aspiring to become CCCs.

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