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Title:

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Date:

2019-10-01

Citation:

Panozzo, S., Collins, A., McLachlan, S. A., Lau, R., Le, B., Duffy, M. & Philip, J. (2019).
Scope of Practice, Role Legitimacy, and Role Potential for Cancer Care Coordinators.
Asia Pacific Journal of Oncology Nursing, 6 (4), pp.356-362. https://doi.org/10.4103/apjon.apjon_29_19.

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Scope of Practice, Role Legitimacy, and Role Potential for Cancer Care Coordinators

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Received: April 17, 2019, Accepted: May 31, 2019

ABSTRACT

Objective: The cancer care coordinator (CCC) role has become a priority in providing coordinated, patient-centered, supported care for patients, and their families experiencing cancer. The CCC role exists with heterogeneity across tumor streams, clinical disciplines, and institutions. This study explored CCCs perceptions and experiences of their role, scope of practice, and potential for future role development. **Methods:** This research used a mixed methods design. Focus groups and individual interviews were conducted with a purposive sample of 16 CCCs from two tertiary public teaching hospitals in Melbourne, Australia. A thematic analysis approach was used. A quantitative record of relative time spent on tasks was also collected. **Results:** Three major themes were identified: (1) Perceptions of role legitimacy, (2) Structure

and funding of the role determines scope of practice, and (3) Reflections on the potential for the role. Variability was evident in predominant tasks undertaken, integration into the unit, level of patient contact, and regard from other professional colleagues. Variability appears to relate to employment time assigned to the role, and history and structure of the role. **Conclusions:** The findings underline the need when establishing and reviewing CCC roles for explicit attention to be given to the reporting, integration, structural, and collegiate support for the role as this will profoundly influence its success.

Key words: Cancer, cancer care coordinator, nurse specialist, patient care management, patients

Introduction

The management of cancer care is complex with patients frequently receiving sequenced or concurrent systemic therapies, surgery, and radiotherapy, and navigating between different tumor streams, clinical disciplines, and institutions

over time. In the Australian context, cancer patients have reported value in support of an experienced clinician to coordinate their care, to assist them to navigate between arms of health service provision, and to provide them with

Access this article online

Quick Response Code:



Website: www.apjon.org

DOI:
10.4103/apjon.apjon_29_19

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Cite this article as: Panozzo S, Collins A, McLachlan SA, Lau R, Le B, Duffy M, *et al.* Scope of Practice, Role Legitimacy, and Role Potential for Cancer Care Coordinators. *Asia Pac J Oncol Nurs* 2019;6:356-62.

a central point of contact for support and information in their care.^[1] The role of a cancer care coordinator (CCC) to provide such coordinated, patient-centered, and supported multidisciplinary care for cancer patients and their families/carers have become a recognized priority both nationally and internationally.^[1-7]

In Australia, there has been variability in the establishment of the CCCs role, scope of practice, professional experience, and funding across tumor streams, clinical disciplines, and institutions.^[1,8-13] This challenge appears to be universal, with international studies indicating role variability and ambiguity, insufficient organizational support for the role, and inconsistency in recognition of the role within the clinical setting.^[6,14-17] This heterogeneity in how the roles are enacted, funded, and function within and across tumor streams or settings may effect the scope of practice, time with patients, and understanding and recognition of the CCC role by other health professionals and management.^[4,8,11,12]

Previous research reveals the CCC role can be constrained by an inadequate allocation of time, funding, lack of administrative support, and/or lack of appropriate physical space to consult privately with patients, which serves to limit the delivery of best-coordinated care.^[1,4,18] Yet studies have shown improved patient and health service outcomes are apparent where there is adequate time for scope of practice to include regular, in-person contact, and follow-up with patients.^[13] CCCs have identified several important enablers to providing effective coordinated care for patients, including working within a supportive team with an integrated and recognized role, effective communication between colleagues, peer support, and provision of administrative support.^[1,8,13,19,20]

While previous studies have focused on patient outcomes, patient and family experiences, and cost-effectiveness of the CCC role,^[13,17] this project sought to specifically focus on CCCs' perceptions of, and preferences for, the development of their role. With increasing evidence to support the benefits of care coordination,^[13,21] it is critical and timely to examine the current CCC role within the Australian context. This study aimed to explore CCCs' perceptions and experiences of their role and scope of practice, with a view to identifying opportunities for the future development of the role.

Methods

Setting

Cancer services within two metropolitan tertiary teaching hospitals with large cancer patient clinical caseloads in Melbourne, Victoria, Australia. Organization around cancer care in these services is based on cancer streams,

and a CCC is assigned responsibilities to a particular cancer or tumor stream such as, for example, lung cancer or head-and-neck cancer. The study was approved by and conducted in accordance with the ethical standards of the Human Research Ethics Committee at the lead study site.

Study population, recruitment and sampling

All CCCs with at least 1-year experience working in their role were eligible for study inclusion. Potential participants were identified by their heads of cancer services, and purposively sampled from across a range of tumor streams, part-time and full-time employment, and two hospital sites. CCCs were invited via E-mail to participate in focus groups by the researchers (JP [clinician/researcher], SP [researcher]) who were independent from the clinical cancer services. Focus groups were chosen to provide opportunity for participants to engage and discuss experiences in a shared forum. Where CCCs were unable to attend focus groups due to part-time work or other commitments, an alternate individual interview time was offered to these select participants.

Those interested in participating contacted the authors and a member of the research team organized attendance to a focus group or interview at a time and site convenient to them. All participants were provided with a study information sheet and written consent obtained at the time of the focus group or interview.

Study design and data collection

This study used a mixed methods design. Qualitative focus groups and individual semi-structured interviews were conducted during 2017–2018 with CCCs and facilitated by three of the researchers (JP, AC, and SP) to explore participants' experiences of their CCC roles. Focus groups and individual interviews were each of 40–60-min duration.

Demographic data were collected using a study-specific questionnaire. Based on the literature, the research team (which included a palliative care specialist, oncologist, and research fellows) developed semi-structured open-ended questions as a guide to explore participants' experiences and perceptions of the CCC role. Questions comprised of the following topics: (i) a description of the CCC role and services; (ii) what, if any, current practices or workload are not considered to be part of the role; (iii) a description of their line of reporting, access to clinical support and advice, and/or professional mentoring; and (iv) perceptions of the ideal practices/role of the CCC and appropriate preparation, development, mentorship, and support included. Further probes were used to elicit greater detail, follow new lines of inquiry or clarify emerging themes dependent on participants' responses. Ongoing data

collection was undertaken concurrently with analysis until saturation of themes was reached. Focus groups and individual interviews were digitally recorded and transcribed verbatim.

In addition to the qualitative arm, quantitative data were collected by use of a diary, with participants asked to record the relative time (%) spent on a series of common clinical, administrative, and other tasks undertaken in their role over a designated week. These were recorded by participants on a paper-based pro forma. Included tasks were informed from the literature, with an “other” section included to allow free text entry of alternate activities.

Statistical analysis

A thematic analysis approach^[22] was taken to analyze focus group and interview transcripts and guided by the discussions exploring structural factors influencing CCCs roles. To ensure anonymity, participants were deidentified within transcripts before being analyzed by two researchers (SP and AC) and discussed with a third researcher (JP) for refinement and consensus. Thematic analysis involved generating initial codes from across the data, collating data into relevant codes, organizing codes into emerging themes, and reviewing and defining these themes.^[22]

Results

A purposive sample of 16 CCC participants was recruited into the study. Three focus groups and two interviews were conducted with a total of 16 participants, including 14 included in focus groups and 2 in individual interviews. All participants were female, and were very experienced, with median length of time nursing of 21 years. Time spent in the CCC role varied from 1 to 15 years, with median full-time equivalent (FTE) of 0.6 FTE (range 0.2–1.0). Participants provided care coordination for patients across a range of cancer types [Table 1].

Diary of cancer care coordinator tasks

Time spent on the various tasks of CCC is detailed according to employment status in Table 2. CCCs with smaller overall employment time spent relatively more time on administrative tasks and less time on patient contact. Those whose employment time allocation were 3 days or less per working week spent almost 50% of their time on administrative tasks, such as booking patient appointments.

Thematic analysis revealed three major themes, including: (1) perceptions of role legitimacy, (2) structure and funding of the role determines the scope of practice, and (3) reflections on the potential for the role. These themes were consistent across all participants.

Table 1: Participant characteristics (n = 16)

Characteristics	No. of participants, n (%)
Gender	
Female	16 (100)
Years of nursing experience	
Median (range)	21 (6-40)
Years in CCC role	
Median (range) [†]	6 (1-15)
Employment status (FTE)	
Full time (1.0) [‡]	6 (37)
Part time (0.2-0.6)	10 (63)
Median (range)	0.6 (0.2-1.0)
Sites	
Site #1	8 (50)
Site #2	8 (50)
Cancer types	
Head and neck	3 (19)
Breast	3 (19)
Lung	3 (19)
Gastric	2 (13)
Urology	1 (6)
Brain	1 (6)
Melanoma and skin	1 (6)
Pediatrics	1 (6)
Sarcoma	1 (6)

[†]FTE; [‡]n=15. CCC: Cancer care coordinator, FTE: Full-time equivalent

Perceptions of the cancer care coordinator role

How cancer care coordinators viewed their role

Most participants described being an integral part of the team and a medical interpreter for their colleagues and patients. These CCCs felt valued, with their contributions perceived as important and a legitimate, even essential part of the system of care delivery. Direct contact with and support of patients was associated with this sense of valued contribution.

“It’s just that kind of close working relationship, that we’re almost that medical filter to them, and then that feeds back to the patients, when the doctors come in and give them a diagnosis and walk out, we’re then that filter of, now let’s make this a human experience of what’s that treatment and diagnosis discussion actually mean for you as a person”) Focus Group 3)

However, other CCCs viewed their role as isolating, lonely, and entirely administrative, with only limited (if any) patient contact. This was predominately expressed by CCCs who had less FTE available to undertake their duties, meaning roles were instead largely restricted to the tasks that were essential to their key role of multidisciplinary meeting coordination.

“My role is for eight hours in a week and it’s entirely administrative. Usually I’ll talk to a patient because they’ve stumbled across me, not because I’ve been introduced to them. Which is a shame because there’s a lot of value-add that as an

Table 2: Mean percentage of time spent on tasks according to full-time equivalent roles^{†,§}

Tasks	Mean % of time spent on tasks [‡]			
	0.4 FTE (n=2)	0.6 FTE (n=5)	1.0 FTE (n=6)	Total (n=13)
Patient contact				
Face to face	5	17	19	14
Telephone/indirect	10	9	19	13
Family contact				
Face to face	1	7	6	5
Telephone/indirect	1	6	9	5
Health-care professionals				
Face to face	15	13	10	12
Telephone/indirect	15	6	8	9
Administrative tasks				
Arranging appointments for patients	15	24	16	18
Organizing meetings	30	12	6	16
Education/support				
Of other health professionals	5	2	1	3
Professional development	0	0	2	1
Attending patient related meetings	4	4	4	4
Total	100	100	100	100

[†]FTE refers to allocated time per week in employment, where 1.0 is full time or 5 days per week, while, for example, 0.2 is equivalent to working 1 day per week. [‡]Due to rounding, percentages may not add up to 100%. [§]Missing data: 1 x 0.2 FTE; 1 x 0.4 FTE; 1 x 0.6 FTE. FTE: Full-time equivalent

experienced nurse I can give to a patient with a new cancer diagnosis.” (Focus Group 1)

How others viewed the cancer care coordinator role

The CCCs reported variability in how others in the team viewed their role. Some felt they were considered the go-to person and troubleshooter.

“we ... have a lot of contact with everybody on the team so it's almost like you're a natural go-to person because you've got insight into so many aspects and non-threatening and a safe environment.” (Interview 1)

Others noted they were seen as a “doctor’s secretary” and that their skills and contribution as experienced nurses were not always recognized.

“Sometimes I've even said to medical (colleagues), “I didn't spend thirty years as a cancer nurse to be your secretary”.... this is a role that emerging data and common sense tells us this makes a difference for patients, and they (nurses) end up secretaries and the patients miss out.” (Interview 2)

Structure and funding of the role determines the scope of practice

Collegiate support for the cancer care coordinator

The CCC's described the level of clinical support for their activities varied between services. Most felt comfortable seeking advice and support from the oncology services within which they worked and described readily making (and responding to) inquiries from head of service, nurse unit managers, consultants, registrars, and junior doctors. Many CCCs reported having a key clinician from whom they sought advice around medical issues raised by patients or their carers. Whether this collegiate support was

of a formal or informal nature, having medical support to assist with problem-solving of complex issues that may be reported to them was identified as important. Others did not identify a key supportive colleague but instead directed their inquiry according to the patient's primary doctor.

“We're lucky in our unit that we could go to the registrar first, or if there's something about a patient and I know they're from somebody's rooms I'll just call the surgeon directly and they'd be happy for that, or radiation or oncology.” (Focus Group 1)
We've got a head medical oncologist, a head radiation, and a head surgical and then we've got a tumour stream head. So, if it was a particularly complex medical oncology patient, I would go to my medical oncology head and say, “FYI, this is what's happening with an oncology patient at the moment.” But if it was a particularly complex radiotherapy patient, I would make sure that head (of radiation oncology) was aware that this patient is causing these issues. (Focus Group 3)

Peer relationships between the CCCs who worked both within and across tumor streams were considered immensely important to resolve clinical problems and provide support. Many CCCs reported their CCC peers were their first point of call, particularly in dealing with the more emotional aspects of the CCC role. For CCCs who had roles that allowed them to provide continuity of care to patients over many years, and in the setting of progressive disease, the support of other CCCs was essential in enabling them to cope with the challenges they faced.

“So ‘peer name’ and I debrief a lot together, and that's really important, I don't think, I couldn't certainly do this role on my own. I think it's really important to have that support with each other to be able to talk.” (Interview 1)

"I'll bounce ideas off the girls in the office. If it's clinical, patient related, specifically unit related I will talk to the head of the unit, but if it's kind of outside those areas I'll bounce ideas off the girls in the office." (Focus Group 2)

Structural support for the cancer care coordinator role

Material support for the role varied substantially within and between sites as evident in the differences in the level of employment time – some working full time, while others' role was just 1 day/week. Variation also existed in the CCC's reporting lines which frequently arose from the history of the establishment and funding of the roles. This had implications for the tasks and activities undertaken within the role. For example, those whose role was established and funded by a key surgeon will report to that surgeon and will likely focus upon aspects of the cancer diagnosis and treatment relevant to surgical practice.

"...my funding once again comes out from the surgeons, and the surgeons only see my role as in that little bit, and that's just the tip of the iceberg." (Focus Group 1)

The amount of patient contact was related, at least in part, to the overall time available (those with less time reported limited time for patient contact), as well as a lack of space, and the material support for enabling infrastructure.

"I have found (my role) is predominantly data entry and I'm not happy with the amount of time I'm spending with the patient." (Focus Group 2)

"I've tried to have more patient contact in the clinic, but we haven't even got enough rooms for the doctors so it's not like I can sit down and talk to a patient." (Focus Group 1)

Reflections on the core elements of the most effective cancer care coordinator role

CCCs proposed the ideal role structure to be a well-defined position with adequate employment time and appropriate acknowledgment of significant experience and skills in cancer care. The role would have a focus on a small number of tumor types, thereby facilitating professional development in the area, and would have access to administrative support.

"So I think these roles, ideally, (should be) full time." (Focus Group 1)

"A more defined patient group. Not seven cancers. Maybe, you know just one or two." (Interview 2)

"Where you had excellent secretarial support, working with a medical team that saw you as nothing else but a nurse... (not) an addition to their admin team." (Interview 2)

Rather than focus on providing support to patients at one point of the cancer illness experience, for example, at time of diagnosis of breast cancer, the ideal CCC role was viewed as allowing for care of patients throughout their disease trajectory, extending to supporting those with metastatic disease and also to survivorship.

"All of us actually prefer to have the whole disease trajectory and that's really important." (Interview 1)

"A big part of what needs to happen is survivorship afterwards. You know, it's great that we can provide a good surgery... it's being able to provide services when they're finished with their cancer treatment... (My patients) will live for years and years... and they sort of almost come under chronic disease management rather than acute cancer care. So there's a big part of survivorship that we don't deal with because there's nobody doing it." (Focus Group 1)

Clear suggestions were made for structured professional development, including support for interacting with colleagues from other institutions and learning from the experiences of others. Furthermore, participants highlighted the need for a formal mentoring and clinical supervision program to provide professional support and thereby maintain longevity in the roles.

"To advance your scope of practice as a nurse with that patient (group)." (Interview 2)

"...it's always trying to look objectively and saying 'well we're doing good care but what more can we do?'... Obviously there's lots of areas that can improve ... Going to conferences and ... seeing what people are doing overseas and bringing those things back into our practice I think are really important." (Interview 1)

"One of the things that the nurse coordinator group knows that we need to foster is having the role models amongst us. And those mentors available... being able to have the different generations of the nurse coordinators being able to inspire the younger ones again." (Focus Group 3)

Discussion

This study highlights the variability in which CCC roles are enacted in cancer care, varying substantially across and even within two related and geographically close institutions. This variability was evident in the predominant tasks undertaken, the degree of integration into the cancer care unit, the level of patient contact, and the regard for the CCC from professional colleagues. Much of this variability appears to relate to the level of employment time assigned to the role, the history of the role and its structure including its funding source. These key factors influenced how the role was realized in practice.

Those CCCs with less employment time appear to spend proportionately more time on administrative tasks which take priority and then, only if time permits, have direct contact with patients. Some of these roles with few employment hours were established with the explicit requirement to streamline the administrative aspects of patient care, hence the prioritization of tasks. Yet, simultaneously, the patient contact appears to confer greater satisfaction for the CCCs. It is likely that the impact

of a role which includes greater patient contact rather than primarily based on organizational tasks will be most effective in yielding benefits. A systematic review of the role of CCCs has highlighted that those that appear most successful in achieving high impact quality care are those that involved regular, in-person contacts with patients with the ability to provide follow-up monitoring and facilitate transitions in care.^[13] Furthermore, it appears that patient contact also confers greater job satisfaction for CCCs. In this study, the mismatch between the CCCs skills of very experienced cancer nurses and the need to perform extensive administrative tasks was a source of dissatisfaction and contributed to the CCCs sense of being undervalued.

The CCCs saw their predominant relationships and hence collegiate support as being available from within the tumor stream with which they were associated. They sought advice and clinical support from their clinical cancer colleagues and valued their integration within the units. Much of this collegiate support was centered around individual patient coordination and responding to needs. Peer relationships with colleagues working within similar areas, for both CCCs and cancer clinicians, have been suggested to be protective against burn out for cancer care providers.^[19,23] It is important to note that these relationships and hence support from colleagues working within the same tumor stream were less available to those CCCs who did not have significant patient contact.

Finally, the CCCs had clear ideas of what those core components of an “ideal” CCC role should include. They believed such a role should: (i) have sufficient time, (ii) afford the opportunity for patient contact, (iii) be integrated into the tumor stream service, (iv) provide care across the cancer illness spectrum for patients with that particular cancer, and (v) include sufficient support including career development and mentoring support. Although the benefits of CCCs are not unequivocally established with pooled studies suffering from heterogeneous models of delivery, patient populations, those components associated with improved patient outcomes identified in a systematic review, mirror those activities considered by our participants to be core to the ideal role.^[13] The additional component to the ideal CCC position identified in our study and not previously emphasized, is that of support for career development and mentoring. The importance of peer support and mentoring has been realized across many studies, and as highlighted here is highly relevant to well-being and thus the longevity of workers in the CCC roles.^[20]

An example of improved patient outcomes and enhanced CCC satisfaction are available from a pilot study of a structured approach to providing cancer care coordination for patients with high-grade glioma.^[21] This structured

approach, I-CoPE, involves the ideal components of CCC highlighted by participants in this study, notably CCC involvement across the illness spectrum, integration into all aspects of care, prescribed regular contact with patients and carers, and mentored support for the role. Outcomes of a pilot study of I-CoPE reveal preliminary improvements in patient and carer information needs and improved carer quality of life. Hence, in addition to the potential for enhanced CCC satisfaction, these preliminary I-CoPE data point to the possibility of improved outcomes for patients and families, when the “ideal” CCC role is enacted.

Limitations

While the study involved participating CCCs from a range of different tumor streams, the study sample was limited by all participants being nurses, female, very experienced, and from two metropolitan public hospital settings. Although this may not represent the full range of CCCs including those from private hospitals or regional settings, this is the predominant demographic and professional group fulfilling these roles, and completely representative at the institutions where the study took place. And while the sample strongly reflects a particular demographic, this study nevertheless details the variability in roles even at closely associated institutions working in the same publicly funded health-care system.

Conclusion

The establishment of CCC roles has followed a variable historical path, and this has ongoing implications for how these roles are enacted and function, including the long viability. Nevertheless, CCCs value the opportunity for integration of their role into the tumor stream unit and value the experience they bring to responding to patient needs. Opportunities to enhance and further develop the role of CCCs are evident in the provision of administrative support for the role, enabling and facilitating a focus upon all points of the cancer illness and support for professional development, including mentoring. When establishing and reviewing CCC roles, consideration should be explicitly given to the structures around reporting, integration, and collegiate support for the role, as these will profoundly influence its success.

Acknowledgments

We are grateful to all CCC participants for their contribution to this study.

Financial support and sponsorship

This study was funded through a Research Endowment Fund grant from St. Vincent's Hospital Melbourne, Australia (Grant No. 70205).

Conflicts of interest

There are no conflicts of interest.

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