# The Cancer Nurse Coordinator Service in Western Australia: perspectives of specialist cancer nurse coordinators

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#### **KEYWORDS**

cancer care coordination, cancer nursing, psychosocial care, specialist cancer nurse, service delivery

# **ABSTRACT**

# **Objective**

In Western Australia the cancer nurse coordinator (CNC) role is unique, state wide and situated in nursing. It requires the domains of clinical expert, resource consultant, educator, change agent, researcher and advocate to facilitate seamless coordination of care for patients across metropolitan, rural and remote geographical areas of Western Australia. This study examined the role, function and impact of CNCs from the perspective of coordinators themselves.

# Design

Prospective two-phase mixed method study. This paper reports data from the Self Report Activity Questionnaire in Phase one.

#### **Setting**

The state-wide Western Australian Cancer Nurse Coordinator Service.

#### **Subjects**

Metropolitan and rural CNCs (n=18) who had worked in the role for at least six months.

#### Results

Overall, CNCs spent 70% of time in clinical consultation and 41% of CNCs reported having an educational role. Most CNCs (71%) noted that at least half of their patients had complex psychosocial needs at referral. Key role-related activities related to direct nursing care and patient education were performed most frequently on a daily basis. Tasks related to care management planning, patient advocacy and multidisciplinary clinical care were performed weekly. Strategic, team communication and professional development activities were performed less frequently.

#### Conclusion

Diversity of the CNC role was demonstrated with findings showing that CNCs fulfilled the core components of the specialist cancer nurse. Given the clear need to provide consistent support to cancer patients in an increasingly individualised and integrated manner, we consider the CNC role a fundamental element of quality cancer care.

## **INTRODUCTION**

As a result of significant advances in cancer diagnosis and treatment, the overall 5-year relative survival from cancer has improved from 46% in 1982-1986 to 67% in 2007-2011 (AIHW 2014). The advanced capacity to achieve cure or long term remission has resulted in the delivery of more complex and multimodal treatments to patients over prolonged periods, resulting in multiple care teams and locations of care. Due to therapeutic advances, people previously ineligible for cancer treatment because of advanced disease, side effect burden or confounding comorbidities are now eligible for a new generation of treatments, bringing with them urgency for care coordination and navigation across several treatment teams and centres. This is particularly true for people with more complex needs and those disadvantaged by poor health literacy, rurality, or socioeconomic deprivation (Shen et al 2015; Moorin et al 2011).

Care coordination is recognised as an essential feature of high quality person-centred cancer care and critical to ensure optimal patient outcomes (COSA 2015; Shejila et al 2015). Whilst there is variation in the scope and practice of cancer care coordination, the key attributes include assessment and screening of clinical and supportive care needs; delivery of care consistent with established evidence based guidelines; timely and appropriate referral to multidisciplinary care and services; timely and consistent evidence-based education and information to patients and families (COSA 2015). These characteristics enable continuity of care, another critical element of the cancer care coordinator role (Walsh et al 2011; Aiello Bowles et al 2008).

Some studies have shown the benefit to patients and health service efficiency when nurse care coordinators or 'navigators' are involved in peoples' care (Wagner et al 2014). The study by Wagner et al (2014) highlighted the importance of the four elements of care coordination model as regular communication updates, facilitation of access to medical care, development of individualised care plans and conduct and consistently review care plans. These four elements facilitate the provision of optimal care and outcomes for patients outside of the hospital system.

Nonetheless, results from empirical studies have been equivocal, with limited robust evaluation of where or how nurse care coordinators contribute to improved patient outcomes (Young et al 2014). This has been due in part to a lack of robust measures to evaluate the impact of nurse care coordinators on patient outcomes. Walsh et al (2011), using coorelational analyses, attempted to capture the essential features of care coordination and develop a reliable and valid measure to assess the impact of care coordination roles on patient outcomes, but more work is needed to further refine our ability to tailor and target Cancer Nurse Coordinator (CNC) interventions and evaluate the impact of such interventions.

A qualitative study by Baker et al (2013) of breast, lung and prostate cancer patients during 18 months post diagnosis demonstrated the impact of poorly coordinated care and lack of a single point of contact on patient experience and emotional wellbeing as well as routine assessment. Potentially, even within the best case scenario following diagnosis, coordination of cancer care and effective ongoing communication between all parties can be compromised. Furthermore, the trajectory of the disease spans a considerably greater timeframe than the active treatment phase alone. During this time, patients can find themselves in a state of confusion over a number of issues around the management of their condition leading to maladjustment. If positive adjustment is not identified and dealt with early following diagnosis then anxiety and depression can worsen as the person enters the 'survivorship' phase (Schumacher et al 2013).

# The status of Cancer Care Coordination in Australia

The Optimising Cancer Care in Australia report (COSA 2003) highlighted the complexity of the management of individuals with cancer given the need for multiple care providers across different care settings and over a considerable time frame. With limited process and systems to deliver coordinated care, the capacity to

construct health care around the needs and preferences of patients, although increasingly recognised as the gold standard for cancer care (Kvåle and Bondevik 2008), in reality is often extremely difficult to achieve. Some studies have shown this requires a fine balance in terms of managing individual preferences in relation to the coordination of their care given the involvement of many health professionals across the illness trajectory through to survivorship phases of cancer (Thorne et al 2013; Brown et al 2012; Campbell 2006; Arora 2003).

To address these concerns, the Optimising Cancer Care in Australia (COSA 2003) report advocated for the need to provide integrated multidisciplinary care and proposed that optimal cancer treatment for all individuals would lead to improved survival, quality of life and smooth transition through the cancer journey. In response, the CNC role was introduced in many states of Australia but with considerable variation in scope, level of practice and function.

#### The context for this study

In Western Australia achieving care coordination for cancer patients is particularly challenging. The state spans 2,500,000 square kilometres and accounts for 30% of Australia's land mass with 38% of the population located in rural and remote areas (Australian Government 2007). Although 38% of the population are located in rural and remote areas, multimodal cancer treatments are only delivered in metropolitan Perth, and Bunbury in the south western corner of Western Australia. The disparity in availability of multimodal cancer treatments impacts access to and cost of care and treatment, potentially resulting in suboptimal outcomes for sectors of the population, for example, those residing in rural Australia, the older sectors of the population along with those from Aboriginal and Torres Strait Islander backgrounds.

A state-wide service utilising CNCs was implemented in 2006 as a key element of the Western Australian Cancer and Palliative Care Network. The CNC service was established to ensure, every person with complex care coordination requirements benefitted from a one-on-one relationship with a CNC; to facilitate navigation of the cancer care system for patients and their families; ensure timely access to multidisciplinary care teams and treatment decision making; and to provide a central point for consistent information and support across the cancer treatment pathway. The point of difference between a CNC and a nurse aligned with a ward, unit or clinic is that the CNC 'travels' with the patient, assessing symptoms/needs and managing care by modifying and adapting the patient's road map in line with current needs and preferences. No other role currently exists within the cancer environment with similar functions and accountabilities. By embedding CNCs across the state, the role functions could be tailored to the needs of differing patient groups depending on their level of health literacy, diagnosis and location (metropolitan or rural). The metropolitan CNC (mCNC) roles were developed to provide tumour stream specific support and advocacy for patients and families, while the rural CNC (rCNC) roles were introduced to provide broad cancer support and advocacy to patients in their regions. For rural patients requiring treatment in metropolitan Perth the CNCs functioned to provide coordination of care through partnership with Perth based tumour specific mCNCs. All of the mCNCs were and continue to be employed by the WA Cancer and Palliative Care Network. The rCNCs are employed in partnership with WA Country Health Services and are region-specific; they provide care to patients with all cancer types, interact with the rural and the metropolitan health care system and are exclusively used by rural patients. The rCNC positions are funded by the WA Cancer and Palliative Care Network with CNCs employed by and operationally responsible to the WA Country Health Service. Uniquely, CNCs were not located within a clinical environment allowing them the opportunity to interface with both patients and multidisciplinary professionals in a diversity of clinical and health environments.

#### Study aims

A study was undertaken to explore the contribution of both the mCNC and the rCNC roles to meeting the goal

of the WA Health (Cancer) Services Framework (2005) in delivering a coordinated and streamlined approach to cancer care coordination for patients across the state. The objectives of the study and subsequent paper were as follows:

- to describe the CNC perception of the impact of their role;
- to examine roles and functions for the CNC role; and
- · to explore factors that influenced the implementation of their role either positively or adversely.

Data were gathered from CNCs and the patients they cared for, patient informal carers and multidisciplinary colleagues between 2008 and 2010. This paper only reports findings from the first phase of this study which evaluated the role using survey methodology from the perspective of rural and metropolitan CNCs. Data from patients, carers, health professionals and the qualitative CNC component will be reported in subsequent manuscripts.

Ethical approval for the study was obtained from participating hospitals across Western Australia.

## **METHODOLOGY**

The study adopted a prospective two-phase, exploratory design applying sequential mixed methods that used quantitative (survey) and qualitative (semi-structured interview) approaches to data collection. As previously noted, this manuscript will focus on the extensive survey findings from the CNC perspective. Data were transcribed into SPSS and analysed by an independent statistician to ensure independence of researchers to the analysis process.

#### **Data collection**

Prior to embarking on the first phase of the study, the clarity, internal consistency and content validity of an adapted version of the 99-item Evercare Nurse Practitioner Role and Activity Scale (ENPRAS) (Abdallah et al 2005) was undertaken. The ENPRAS was chosen for relevance and suitability in the Australian context. Six CNCs were invited to review the ENPRAS questionnaire and provide feedback regarding any missing items or requirement for clarification of wording. This process resulted in the addition of 66 items, resulting in a 165 item questionnaire, renamed the Self Report Activity Questionnaire (SRAQ). Details of the process undertaken to establish internal consistency, based on the works of (Imle and Atwood 1988; Lynn 1986; Aamodt 1983) are available from the authors.

The 165 items made up 11 subscales covering: direct nursing care; clinical care management; patient education in the clinical context; care management plan; patient advocacy in the clinical context; multidisciplinary clinical care; multidisciplinary team meetings; education services; strategic tasks; professional development; and team communications

Following a rigorous process to establish internal consistency of the adapted questionnaire, the SRAQ was found to have a high degree of internal consistency with an overall Cronbach's alpha coefficient of 0.976, and individual subscale Cronbach alpha coefficients ranging from 0.421 to 0.957. The original ENPRAS had a content validity index of ≥0.78 for all items and internal consistency reliability Cronbach's alpha scores ranging from 0.76 – 0.96 for subscales (Abdallah et al 2005).

# Phase 1: Administration of the Self Activity Report Questionnaire (SARQ) Sample population

All CNCs with at least six months experience working in the role were eligible and invited to participate in the study. At the time of the study, 20 CNCs were employed in the service, 18 of whom were eligible to participate and were invited to complete the SARQ.

## Recruitment and data collection

Following education sessions regarding the purpose and scope of the study, CNCs were sent an information sheet providing details about the rationale and requirements of participation in the study and a copy of the study questionnaire. Where nurses completed and returned a questionnaire, consent was implied as is the standard process with survey distribution. Implied consent for survey data was approved by the HREC committees and was considered usual practice when sufficient information about the survey purpose and content has been given (Alessi and Martin, 2010)

# Data analysis

Due to the small number of participants, descriptive statistics were applied to the majority of the data. Nonparametric tests (Mann-Whitney) were used to determine if there were any significant differences between metropolitan and rural CNC grouped data and continuous responses. Analyses were performed by an external statistician to ensure independence of analytical procedures and findings. A random sample of 10 percent of returned questionnaires were checked for data entry errors and no systematic errors were noted.

#### **FINDINGS**

Eighteen surveys were returned by the CNC participants (100% response rate). Given that there were two groups of CNCs by location (metropolitan and rural) this study explored the functional aspects of the CNC role, but also whether there were any trends between the two groups. Hence, while there were some differences in responses provided by metropolitan and rural CNCs it was not possible to reliably assess for significant differences across the groups.

## **Demographic characteristics**

The average length of time the participants had been nursing was 18.6 years  $\pm 7.0$  fulltime and 8.0 years  $\pm 6.6$ part-time. CNC repondents had been working with cancer patients for an average of 9.5 years ± 5.9 and the average length of time in the CNC role was almost two years (M=1.9; range:0.4 - 2.4) Qualifications included Graduate Certificates (n=12), one Master of Nursing and one Nurse Practitioner (Masters qualification).

# Functions of the CNC role and patient caseload.

The mean patient caseload per CNC over the six month period preceding the data collection was 88.5 ±39.7 patient referrals, approximately 15 new referrals per month. The mean number of interventions performed per CNC was 437.8 ±240.7 approximately 78 per month Interventions delivered by the CNCs were categorised from level 1-5 according to the duration of time taken to deliver each intervention whereby time was used as a proxy for complexity (table 1).

#### Time spent on clinical consultation and non-clinical tasks

The average number of rostered hours per week spent on clinical consultation was 26 hours with 11 hours spent on clinical administrative tasks. Clinical administrative tasks which are core to optimal patient care and included input of written information for patient records and communication with other health professionals to arrange patient transportation/appointments/tests. There was an observed difference in overtime hours between metro and rural CNCs with metro CNCs reporting an average of five hours of overtime and rural CNCs reporting double that with 11 hours average overtime.

# Sources of referral

CNCs were asked to provide a percentage of patient referrals from a number of sources. CNCs estimated that the majority of referrals originated from medical clinicians (19%), other CNCs (17%) along with MDT meetings (14%), and other hospital medical staff (12%). Interestingly, rural CNCs received more referrals from GPs (7%) compared with none (0%) amongst metro CNCs.

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Table 1: Number and complexity of new patient referrals to CNCs during the first six months of role commencement

CNCs n=18	Metro (n=11)	Rural (n=6)	Total (n=17)	Mann-Whitney	
	(11-11)	(11-0)	(11-11)	Z	р
No. new patient referrals	89.6 (37.2)	86.5 (47.8)	88.5 (39.7)	-0.201	0.841
No. patient interventions:					
Level 1	111.0 (114.7)	139.2 (32.6)	120.9 (93.6)	-1.508	0.131
Level 2	153.0 (112.9)	215.3 (142.1)	175.0 (123.4)	-1.006	0.315
Level 3	87.6 (41.3)	111.3 (53.7)	96.0 (45.9)	-1.359	0.174
Level 4	30.5 (30.0)	47.7 (19.7)	36.6 (27.5)	-1.711	0.087
Level 5	8.5 (11.9)	14.2 (6.6)	10.5 (10.5)	-1.715	0.086
Total number of interventions	388.7 (263.8)	527.7 (176.6)	437.8 (240.7)	-1.608	0.108

[Level 1 = 5-10 mins provision of information; Level 2= 10-30 minutes signposting to other services; Level 3 = 30 mins - 1 hour new patient assessment of psychosocial and physical needs; Level 4 = 1-2 hours patient and family support; Level 5 = 2 hours or more complex ongoing intervention as per individual needs]

Table 2: Tasks performed frequently by CNCs

Task frequently performed by CNCs						
	No. respondents (n=17)	% respondents				
5 top tasks performed <u>daily</u> by CNC						
Phone / email correspondence with families	14	82.4				
Manage clinical caseload activity	13	76.5				
Provide patient / families with my contact details	12	70.6				
Conduct psychosocial assessment of patients	10	58.8				
5 top tasks completed <u>weekly</u> by CNC						
Responsible for continuity of patient care	12	70.6				
Care management plan which is patient focussed	11	64.7				
Provide strategies for families to ask questions of health professionals	11	64.7				
Review of assess a patient at health care team request	11	64.7				
Advise or suggest other treatments to patients	11	64.7				
5 top tasks performed monthly by CNCs						
Communicate with palliative care services for transfer of patients	11	64.7				
Communicate with pharmacists on behalf of patients	11	64.7				
Encourage nursing staff to enhance ability to recognise changes in patients	11	64.7				
Meet with key stakeholders to build / promote the CNC role	11	64.7				
Write reports (activity, annual reports etc)	11	64.7				
5 top tasks performed <u>yearly</u> by CNCs						
Attend professional development	17	100.0				
Attend regional meetings	15	88.2				
Present at regional meetings	15	88.2				
Communicate / arrange relevant staff regarding handover cover	15	88.2				
Deliver community education talk	14	82.4				

# **Role related CNC activity**

CNCs reported eleven key role-related activities. Namely, direct nursing care; clinical care management; patient education; care management plan; patient advocacy; multidisciplinary care; multidisciplinary team meetings; education services; strategic tasks; professional development; team communications. Tasks were analysed as either (i) daily (ii) weekly (iii) monthly or (iv) yearly and comparisons made between metro and rural CNC respondents. Table 2 shows top five tasks per daily / weekly / monthly or yearly frequency. The graph below shows an overall representation of the frequency of CNC activities.

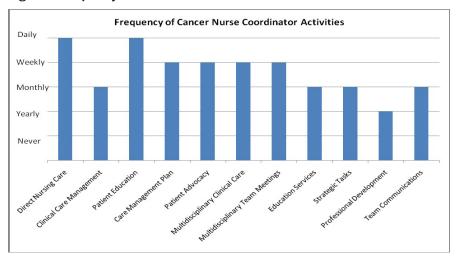


Figure 1: Frequency of Cancer Nurse Coordinator Activities

# **Direct nursing care**

In terms of direct nursing care a majority of CNCs conducted daily symptom management (59%), psychosocial (53%), needs assessments (53%) and physical assessments (47%) of patients. In addition, twenty-four percent of CNCs use an evidence based screening tool to conduct a physical assessment of patients while 18% used an evidence based screening tool when conducting psychosocial or symptom management assessments of patients. In terms of differences between rural and metro CNCs, rural CNCs conducted some direct nursing care related tasks more frequently such as assessment of patients for mild behaviour changes at a daily frequency (50%) compared to weekly for metro CNCs (36%), and meeting with patients in their home at a yearly frequency (67%) compare to never for metro CNCs (82%)

# **Clinical care management**

Daily clinical care management tasks included: discuss queries or health status changes with patient (53%) and family members (47%) and support them as they deal with changes. Tasks performed weekly most often included the identification/assessment and monitoring and follow-up patients with ongoing complex needs (53%).

Fifty nine percent of CNCs conducted bereavement follow-up with families. In terms of differences between metro and rural CNCs, rural CNCs conducted a number of clinical care management tasks more frequently than metro CNCs.

# Patient education in a clinical context

All patient education in the clinical context tasks are performed by CNCs such as education of the patient (53%) and family (47%) about patient disease state and/or progression on at least a weekly basis. When compared to rural CNCs, metro CNCs more frequently conducted all patient education in the clinical context tasks, including education of the patient about patient disease state and/or progression, at a daily frequency (metro CNCs 73% and rural CNCs 83%).

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# Care management plan

In terms of care management planning most CNCs communicated the patient's care management plan daily with relevant health care professionals and educated patients about care management plans and its importance (35%). Metro CNCs more frequently conducted the care management plan tasks when compared with rural CNCs. Rural CNCs revised care management plans for patients more often at a weekly frequency (50%) than metro CNCs who performed this task at a monthly frequency (36%).

#### Patient advocacy in a clinical context

A large proportion (41%) of CNCs interpreted communication to a patient, or family member, by medical staff from culturally and linguistically diverse backgrounds on a daily basis. In addition, the majority of CNCs provided patients and families with strategies to ask questions, or raised issues, during a consultation with a health care professional (59%) and acted as the person responsible for continuity of care for patients (65%) on a weekly basis. In terms of rural and metro differences, although fifty five percent of metro CNC's interpreted or elaborated upon communication to a patient, or family member, by medical staff from culturally and linguistically diverse backgrounds on a daily basis, 50% of rural CNC's performed this task only yearly.

# Multidisciplinary clinical care and team meetings

CNCs provide input to the patient care management team (47%) on a weekly basis. When compared to rural CNCs, metro CNCs more frequently consulted with appropriate discipline specialists about patient's condition changes with metro CNCs conducting this task at a weekly frequency (64%) compared with rural CNCs who conducted this task at a monthly frequency (50%).

#### **Education services**

Forty one percent of CNCs acted as a resource to support nursing or other staff on a weekly basis. Most education services were provided by CNCs on a monthly basis. Education services included educating individuals/groups of nursing, or other staff through informal (41%) and formal education (47%), and encouraging nursing or other staff to seek specific teaching opportunities with the CNCs (65%).

Metro CNCs more frequently conducted a number of professional education services when compared with rural CNCs. However, rural CNCs more frequently acted as a resource and/or support nursing, or other staff at a weekly frequency (67%) compared with monthly by metro CNCs (46%) and supported nursing staff who care for patients with unique needs (e.g. religious or cultural, non-compliance, stress/grief and loss reactions) at a weekly frequency (33%) compared with monthly by metro CNCs (36%).

#### Strategic tasks

Strategic tasks were directed towards service improvement or delivery for the cancer patient population and were less frequently conducted by CNCs compared with other tasks, with many tasks performed on a monthly or yearly basis. Strategic tasks performed by CNCs most frequently on a monthly basis included: meeting with key health providers/organisations to build and promote the CNC role (65%) and communicating or meet with various organisations in order to establish CNC service provision/referral process (47%) and communicating with Clinical Service Directors/Department Heads to discuss issues that impact on patient care (47%).

# **Professional development**

Most professional development tasks were completed on a yearly basis although a majority of CNCs (59%) maintained continuing education and engaging with the latest research related to patient care issues within their clinical stream. The majority of CNCs never prepared papers for publication in peer reviewed journals (58%) or sat on a panel discussion at a regional meeting, state, national or international conference/symposia (65%). When compared to rural CNCs, metro CNCs more frequently: prepared abstracts, papers, or posters for conference presentation at a yearly frequency (64%) compared with never by rural CNCs (83%).

## **Team communications**

Seventy-seven percent of CNCs documented and managed clinical caseload activity data relevant to their role (such as number and level of interventions performed on patients) on a daily basis. When compared with rural CNCs, metro CNCs more frequently: communicated/visited with another CNC in order to learn about their role at a monthly frequency (46%) compared with yearly by rural CNCs (67%) and attended CNC team meetings at a weekly frequency (54%) compared with monthly by rural CNCs (100%). Whereas rural CNCs provided mentoring or orientation to other CNCs or other nurses at a weekly frequency (33%), compared with metro CNCs who conducted this task monthly (54%).

#### **Patient caseload**

A majority of CNCs (71%) perceived that at least half of their patients had complex psychosocial care needs at the time of referral. Complexity was defined as those requiring further intervention such as 'significant psychological distress', 'significant physical impairment' and 'severe physical symptoms' (Clinical Oncological Society of Australia, The Cancer Council Australia, and National Cancer Control Initiative, 2003) all of which (combined or alone) can benefit from specialised interventions (e.g. counselling, psychotherapy, physiotherapy, speech pathology, occupational therapy, fertility services).

At time of referral, the majority of CNCs (71%) reported that approximately 50% of patients had complex psychosocial needs along with a moderate level of functional status which limited their ability to perform normal activity as measured by the Australia-modified Karnofsky Performance Scale (Abernethy et al 2005).

#### **DISCUSSION**

Navigation of the cancer care system can be confusing and stressful for patients and their families (Greer et al 2008; Wells et al 2008; Burgess et al 2005; Jefford and Tattersall 2002) given the plethora of treatments and services that a cancer patient interfaces with during their treatment phase. Data from this study show that CNCs role is key to improving patient experience through helping patients and family members manage the multiple and complex systems and processes involved in cancer service delivery, often over prolonged periods of time. The CNC study allowed the CNCs to identify through a systematic and focused process, factors that enable or hamper them in the implementation and delivery of what has been described by patients as a critically important coordinating function (Crane-Okada 2013). Although the CNCs in this study did not overtly refer to the level of cancer expertise required to be effective in the role, nonetheless, the 'silence' of nursing's articulation of its skill has been powerfully articulated by Buresh and Gordon (2006). Addressing the silence around the articulation of the CNC role and giving a nurses a voice to illustrate where the CNC role value adds to patient experience, may make a valuable impact on the way in which the role is understood, accepted and protected from health cost savings in the future.

Survey findings demonstrated that CNCs who participated in this study expressed diversity within their roles such as: being an advocate, psychosocial support person and services liaison coordinator amongst other clinical functions of the role. However, most importantly the findings demonstrate the diverse elements of their role were drawn together as a package of care relevant to the needs and circumstances of each patient. Furthermore, the purpose and function of the CNC role is to be the single point of contact, the constant in a complex, frightening and unfamiliar context for patients, irrespective of their context or culture. For colleagues, their role and function is to be the point of contact for orientation and communication of the treatment trajectory for individuals within their case load.

The challenge now for CNCs is to undertake robust research that captures and makes visible the impact of this role on patient experience but critically on patient outcomes.

## **LIMITATIONS**

At the time of evaluation, the CNC service had been in progress for several months. While this limited the level of enquiry to a descriptive study, this study was able to evaluate the CNC role from the perspective of patients, carers, healthcare professionals and CNCs themselves. Publication of data from patients, carers and multidisciplinary health professionals is currently in train.

## CONCLUSION

Cancer nurse coordinators are critically important roles in an ever increasingly complex cancer context given the need to provide consistent support to patients. As cancer therapies become ever more personalised, prolonging survival through increasing demand for prescription of life-long therapies, support will become a fundamental element of quality cancer care. Health care providers who traverse care boundaries and communicate across multiple health care teams will be invaluable resources to patients and professionals in this era. The challenge for nursing is to deliver empirical data to demonstrate the patient and system outcome benefits of having experienced cancer nurses in these roles and, equally importantly, when care pathway coordination can be achieved for patients through other members of the health care team. In reality, this will differ from context to context and the challenge for health services considering implementing care coordination roles is to understand the needs of their community in order to ensure that the skills and expertise of CNC resources are appropriately placed to deliver optimal experience and outcomes for people affected by cancer.

## **RECOMMENDATIONS**

Further research is required to truly articulate the contribution of cancer nurse coordination. The art of cancer nursing developed over years of clinical experience combined with the science of contemporary nursing care and health system knowledge needs to be explored to demonstrate the benefits to patients with complex needs, their families and the health system as a whole; from an optimal health care and financial outcome.

#### **REFERENCES**

Australia: an overview. 2014. Cancer series no. 78. Cat. No. CAN 75. Canberra: AIHW.

Aamodt, A. 1983. Problems in doing nursing research: Developing a criteria for evaluating qualitative research. Western Journal of Nursing Research, 5(4):398-402.

Abdallah, I., Fawcett, J., Kane, R.L., Dick, K. and Chen, J. 2005. Development and psychometric testing of the EverCare Nurse Practitioner Role and Activity Scale (ENPRAS). *Journal of the American Academy of Nurse Practitioners*, 17(1):21-26.

Abernethy, A.P., Shelby-James, T., Fazekas, B.S., Woods, D. and Currow, D.C. 2005. The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice [ISRCTN81117481]. *BMC Palliative Care*, 4(7).

Aiello Bowles, E.J., Tuzzio, L., Wiese, C.J., Birlin, B., Greene, S.M., Clauser, S.B. and Wagner, E.H. 2008. Understanding high-quality cancer care: a summary of expert perspectives. *Cancer*, *112*(4):934-942.

Alessi, E. and Martin, J. 2010. Conducting an Internet-based survey: benefits, pitfalls and lessons learned. Spcial work research, 34(2):122-128.

Arora, N.K. 2003. Interacting with cancer patients: the significance of physicians' communication behavior. Social Science and Medicine, 57:791-806.

Australian Government. 2007. Economic Roundup Spring. 2007 (T. Treasury, Trans.) (Vol. 2008). Canberra: Australian Government.

Baker, P., Beesley, H., Dinwoodie, R., Fletcher, I., Ablett, J., Holcombe, C. and Salmon, P. 2013. You're putting thoughts into my head': A qualitative study of the readiness of patients with breast, lung or prostate cancer to address emotional needs through the first 18 months after diagnosis. *Psycho-Oncology*, 22(6):1402-1410.

Brown, R., Butow, P., Wilson-Genderson, M., Bernhard, J., Ribi, K. and Juraskova, I. 2012. Meeting the decision-making preferences of patients with breast cancer in oncology consultations; impact on decision-related outcomes. *Journal of Clinical Oncology*, 30(8):857-862.

Buresh, B. and Gordon, S. 2006. From Silence to Voice: What Nurses Know and Must Communicate to the Public. Sage House, USA: Cornell University Press.

Burgess, C., Cornelius, V., Love, S., Graham, J., Richards, M. and Ramirez, A. 2005. Depression and anxiety in women with early breast cancer: five year observational cohort study. *British Medical Journal*, 330(7493).

Campbell, K. 2006. Methods of meeting patients' cancer information needs. Nursing Times, 102(14):28-30.

Clinical Oncology Society of Australia, 2015. Cancer Care Coordinator Position Statement. November 2015.

Clinical Oncological Society of Australia, The Cancer Council Australia, and National Cancer Control Initiative. 2003. Optimising Cancer care in Australia (pp1-122). Melbourne, Victoria.

Crane-Okada, R. 2013. Evaluation and outcome measures in patient navigation. Seminars in Oncology Nursing, 29(2):128-140.

Greer, J.A., Pirl, W.F., Park, E.R., Lynch, T.J. and Temel, J.S. 2008. Behavioral and psychological predictors of chemotherapy adherence in patients with advanced non-small cell lung cancer. *Journal of Psychosomatic Research*, 65(6):549-552.

Imle, M. and Atwood, J. 1988. Retaining qualitative validity while gaining quantitative reliability and validity: Development of the transition to parenthood concerns scale. *Advances in Nursing Practice*, 11(1):61-75.

Jefford, M. and Tattersall, M.H. 2002. Informing and involving cancer patients in their own care. The Lancet Oncology, 3(10):629-637.

Kvåle, K. and Bondevik, M. 2008. What is important for patient centred care? A qualitative study about the perceptions of patients with cancer. Scandinavian Journal of Caring Sciences, 22(4):582-589.

Lynn, M.R. 1986. Determination and quantification of content validity. Nursing Research, 35(6):382-385.

Moorin, R., Gibson, D., Bulsara, C. and Holman, C.D.J. 2011. Challenging the perceptions of cancer service provision for the disadvantaged: evaluating utilisation of cancer support services in Western Australia. Supportive Cancer Care, 20(8):1687-1697.

Schumacher, J.R., Palta, M., Loconte, N.K., Trentham-Dietz, A., Witt, W.P., Heidrich, S.M. and Smith, M.A. 2013. Characterizing the psychological distress response before and after a cancer diagnosis. *Journal of Behavioral Medicine*, 36(6):591-600.

Shejila, C.H., Pai, M.S. and Fernandes, D.J. 2015. Oncology Nurse Navigator Programme a Narrative Review. *Nitte University Journal of Health Science*, 5(1):103-107.

Shen, M.J., Binz-Scharf, M., D'Agostino, T., Blakeney, N., Weiss, E., Michaels, M. and Bylund, C.L. 2015. A mixed-methods examination of communication between oncologists and primary care providers among primary care physicians in underserved communities. *Cancer*, 121(6):908-915.

Thorne, S., Oliffe, J.L. and Stajduhar, K.I. 2013. Communicating shared decision-making: Cancer patient perspectives. *Patient Education and Counseling*, 90(3):291-296.

Wagner, E.H., Sandhu, N., Coleman, K., Phillips, K.E. and Sugarman, J.R. 2014. Improving Care Coordination in Primary Care. *Medical Care*, 52(11 Suppl 4):S33-S38.

Walsh, J., Young, J.M., Harrison, J.D., Butow, P.N., Solomon, M.J., Masya, L. and White, K. 2011. What is important in cancer care coordination? A Qualitative Investigation. *European Journal of Cancer Care*, 20(2):220-227.

Wells, K.J., Battaglia, T.A., Dudley, D.J., Garcia, R., Greene, A., Calhoun, E. and Raich, P.C. 2008. Patient navigation: state of the art or is it science? *Cancer*, 113(8):1999-2010.

WA Health (Cancer) Services Framework, WA Health Cancer Services Taskforce. 2005. WA Department of Health.

Young, J.M., Masya, L.M., Solomon, M.J. and Shepherd, H.L. 2014. Identifying indicators of colorectal cancer care coordination: a Delphi study. *Colorectal Disease*, 16(1):17-25.