



"Our nurse is the glue for our team" - Multidisciplinary team members' experiences and perceptions of the gynaecological oncology specialist nurse role



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ABSTRACT

Purpose: To determine how members of gynaecological oncology multidisciplinary teams experience and perceive the specialist nurse role.

Methods: Members of gynaecological oncology multidisciplinary teams were recruited via two professional organisations to participate in an online qualitative survey. Survey responses were subjected to an inductive content analysis and categorised according to meaning.

Results: Sixty-six (n = 66) multidisciplinary team members participated in the online survey. Most participants worked in metropolitan areas and within the public health care system. 71% (n = 47) of participants had a specialist nurse working in their team. Participants without a specialist nurse in their team (n = 19) believed that this was a disadvantage to the women in their care except where other experienced nurses were able to fill this void. Key aspects of the specialist nurse role identified by multidisciplinary team members included: Contact, communication, and coordination; Support and advocacy; Knowledge and education; Assessment, referral and management. Concerns and disadvantages relating to the role identified by team members included the development of dependence on the specialist nurse, the impact of large workloads, and the oversight of what other nurses can offer the patients.

Conclusions: This study has contributed the perspective of a key stakeholder, the multidisciplinary team, to our understanding of the gynaecological oncology specialist nurse role. Clearer definition of specialist nurse roles is required. Standardised nomenclature and guidelines for practice are recommended to ensure that the specialist nurse role and their scope of practice are clear to key stakeholders and over-dependence on the individual in the role is mitigated.

1. Introduction

Optimal treatment and care of women with gynaecological cancers requires a multidisciplinary team that includes gynaecological oncologists; medical oncologists; radiation oncologists; nurses with specialist gynaecological expertise; pathologists; radiologists; general practitioners (GPs); gynaecologists; specialist allied health professionals; palliative care providers; sexual health counsellors; geneticists; dieticians; and genetic counsellors (Cancer Australia & The Royal Australian College of Obstetricians and Gynaecologists, 2011; National Gynaecological Cancer Tumour Standards Working Group, 2013). Specialist nurses are considered important members of gynaecological cancer multidisciplinary teams providing comprehensive treatment of gynaecological cancers (Cancer Australia & The Royal Australian

College of Obstetricians and Gynaecologists, 2011; Fung-Kee-Fung et al., 2015; National Gynaecological Cancer Tumour Standards Working Group, 2013; NHS Commissioning Board, 2013).

Studies involving gynaecological oncology specialist nurses were first published in the late 1990s and early 2000s (Carlsson and Strang, 1998; Jefferies, 2002; Maughan and Clarke, 2001). The effectiveness of gynaecological oncology specialist nurse interventions on quality of life, satisfaction with care and psychological outcomes was investigated in a quantitative systematic review of nine studies by Cook et al. (2015). The findings of the review indicated that specialist nurse interventions involving comprehensive or individualised care across all care domains positively affected some aspects of quality of life, patient satisfaction with care, feelings of uncertainty, and sense of coherence (Cook et al., 2015). The quality of the studies included in the review

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was variable and the results must be considered with caution. A qualitative systematic review of seven studies considering women with gynaecological cancers' experiences of specialist nurse care found that women trusted the expertise of their specialist nurse and valued care that was tailored to their needs and easily accessible (Cook et al., 2017). These reviews provide an adequate overview of the perspective of women on the role of gynaecological oncology specialist nurses however only one study among the two reviews was conducted in Australia and none in New Zealand.

Over the past 20 years, the gynaecological oncology specialist nurse role has developed with limited formal direction or control in both Australia and New Zealand. The two countries report similar incidences of each of the gynaecological cancers relative to their population size – 1093 new cases overall in New Zealand and 5564 in Australia in 2014. There are many commonalities and linkages between Australia and New Zealand in regard to the treatment of women with gynaecological cancers. Their similar healthcare systems offer both publicly and privately funded health care and one professional body – The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) – governs the practice of gynaecological oncology medical specialists from both countries. Likewise, the registration requirements for nurses are mutually recognised between the two countries. However, where the roles of nurse practitioners have been clearly defined in Australia and New Zealand, other specialist and advanced practice nursing roles are poorly defined and there are no specific registration or accreditation requirements for these roles. While New Zealand use standard nomenclature and refer to nurses at this level as Clinical Nurse Specialists, their role remains poorly defined (Cumming, 2012; Roberts et al., 2011). In Australia, there is no formal definition or standardised nomenclature for this level of nursing. There are no standardised guidelines for practice or minimum education or experience requirements currently in place to direct the specialist nurse role in gynaecological oncology. Hence, for the purpose of this study, the specialist gynaecological cancer nurse is identified as a nurse engaged in specialist or advanced practice in the care of women with gynaecological cancers under role titles, including but not limited to, Clinical Nurse Specialist, Clinical Nurse Consultant, Cancer Nurse Specialist, Cancer Nurse Coordinator.

In Australia and New Zealand the inclusion of a specialist nurse in a gynaecological oncology team, and their scope of practice, is at the discretion of their employing health service. Although recommended, access to a specialist nurse is not standard for all women treated for gynaecological cancer in Australia and New Zealand. This has resulted in disparate service offerings and variability in scope of practice. When services differ so greatly, forging a formal identity for the role that has a defined career and education pathway for aspiring nurses is problematic. There is thus a need to explore how the gynaecological oncology specialist nurse role is practiced and formally define the role in the context of the Australian and New Zealand healthcare systems.

Standardised education and career pathways and clearly defined scope of practice are important aspects of role identity and recognition. The specialist breast nurse role in Australia is easily identifiable due to the establishment of minimum education requirements, a defined career pathway, models of care and competency standards to guide practice (Kruss et al., 2014; The National Breast Cancer Centre, 2000, 2005). A similar role identity has not been established for gynaecological oncology nurses in Australia and New Zealand. Where limited studies to date have investigated the specialist nurse role from the perspective of women with gynaecological cancers, it is important to address that the specialist nurse role extends beyond that of direct patient care. Specialist nurses also play a role within the multidisciplinary team and between their organisation and other health services. Multidisciplinary team members were included in the development of the specialist breast nurse role in Australia (The National Breast Cancer Centre, 2000) and capturing the perspectives of all key stakeholders is essential in better defining the role of the specialist

nurse in gynaecological oncology. The objective of this study was to determine how multidisciplinary team members experience and perceive the gynaecological oncology specialist nurse role. This qualitative survey was part of a larger study aimed at describing and defining the role of specialist nurses in the provision of gynaecological cancer services in Australia and New Zealand.

2. Methods

2.1. Setting, participants and procedures

Health care professionals directly involved in the provision of care of women with gynaecological cancers in Australia and New Zealand were invited to participate in this study. As women with gynaecological cancers are treated at multiple centres (> 20) across the two countries, recruitment occurred via two professional bodies – The Australia and New Zealand Gynaecological Oncology Group (ANZGOG) and Cancer Nurses Society of Australia (CNSA). Members of the two organisations were invited to participate in this study via e-mail. The study was also advertised at the 2016 ANZGOG and CNSA annual conferences where brochures were offered to delegates, and snowball sampling was also employed. At the time of recruitment CNSA and ANZGOG had 1000 + and 700 + members respectively however not all members would be directly involved in the care of women with gynaecological cancers. The gynaecological oncology specialist interest group of CNSA had 135 members at the time of recruitment. As the study was qualitative, a statistically representative sample was not relevant. Rather, maximal variation among participants in regard to state/territory/region of work, sector of work, and discipline was sought given the disparate nature of the role within and between jurisdictions. Thus, the sample size was not based on data saturation but maximal variation of both participant characteristics and their experiences and perceptions (Thorne, 2016).

The most conventional ways to capture individual or group experiences and perceptions of a phenomenon in a qualitative study is to conduct interviews or focus groups (Thorne, 2016). However, due to the lack of standardisation of specialist nursing roles, a small sample of in-depth interviews would not have captured the breadth of difference among specialist nursing roles across the two countries. Thus, a qualitative survey methodology was chosen for this study to capture the views of a larger number of multidisciplinary team members. The survey method also allowed for anonymous participation, which was deemed important given the relatively small size and familiarity of the gynaecological oncology community of practice in Australia and New Zealand. An electronic qualitative survey was developed to determine the experiences and perceptions of multidisciplinary team members regarding the specialist nurse role. The survey was created utilising Qualtrics[®] software (Qualtrics LLC, 2015) and comprised mainly of open-ended questions. The survey questions were researcher-derived though modelled on the interview guideline used for treatment team participants in the development and evaluation of the specialist breast nurse model of care in Australia (The National Breast Cancer Centre, 2000). Fig. 1 provides a brief outline of the survey. A limitation of the anonymous survey method was the need for participants to self-identify as a gynaecological oncology health professional. Verification of the professional status of each participant was thus not possible and to do so would have identified the participant.

The survey was open to participants from April 14, 2016 to August 21, 2016 and was closed once representation from all population subgroups of interest had been gained. A reminder was sent to ANZGOG and CNSA members and the survey was closed three weeks thereafter. No further responses had been received in the two weeks prior to closure. The survey was piloted to determine face and content validity by several academics with knowledge and experience in nursing specialisation, and a nursing expert in the field of gynaecological oncology. The survey was reviewed by an expert in survey design to ensure easy

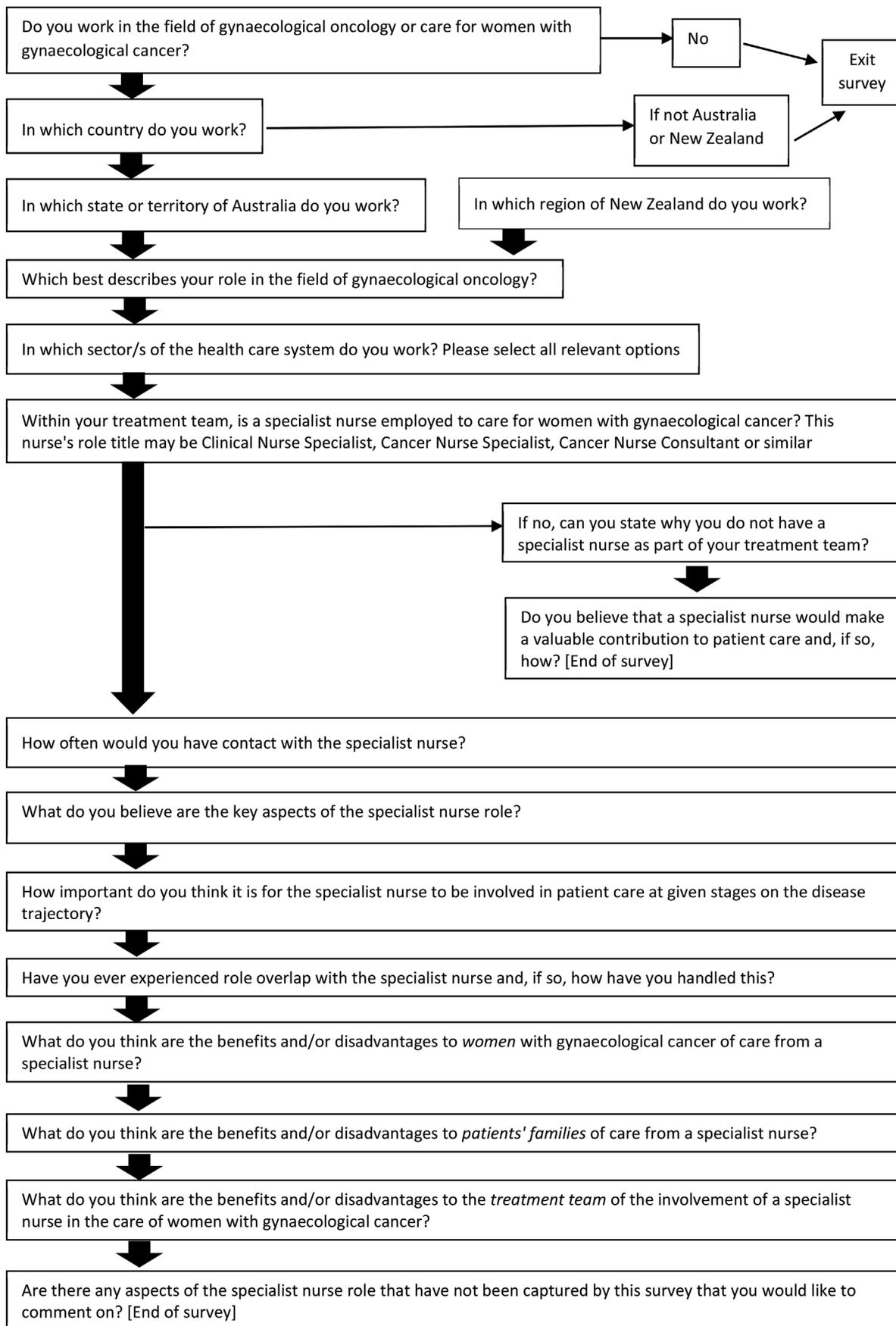


Fig. 1. Survey outline.

export of data between Qualtrics[®] and NVivo Pro[®]. As this was a qualitative study, and the purpose of the survey was to determine experiences and perceptions, it was not necessary to measure statistical reliability or internal, external or construct validity of the tool.

2.2. Data analysis

Survey responses were subjected to a qualitative inductive content analysis. An inductive content analysis method was selected over a deductive method on the basis that the perspectives of treatment team members had not previously been explored and prior theory on the topic did not exist (Elo et al., 2014). During the organisation phase of data analysis, participant responses were extracted and coded by the primary author to minor categories according to meaning in NVivo Pro v.11[®]. Minor categories of similar meaning were then grouped to form major categories. The 'trustworthiness' of this process was examined through consultation with the research team (Polit and Beck, 2010). The minor and major categories were presented to the research team along with extracts of data upon which the minor categories were formed. Over several meetings, the research team audited the inductive content analysis process, discussing and verifying the minor and major categories developed by the primary author against the data extracts (Polit and Beck, 2010).

3. Results

3.1. Participant characteristics

Sixty-six members of gynaecological oncology multidisciplinary teams responded to the survey. Participant's responses for individual open-ended questions ranged between 1 and 238 words in length with an average of 30.5 words. Collectively, medical professionals were the largest sub-group of respondents and accounted for 39.4% (n = 26) of participants. The next largest group to have responded were nurses in roles other than specialist nurse roles accounting for 36.4% of respondents (n = 24). This group included nurse practitioners, nurse educators, nurse managers and registered nurses. Table 1 below shows the professional specialisation of respondents in relation to their country of work.

3.2. Geographical location & sector

Participants were asked to identify the geographical location of their workplace. The majority of participants, 65.2% (n = 43), worked in a metropolitan area only as indicated in Table 2. Survey respondents were also asked to identify the sector of the health care system that they worked in. As shown in Table 3, most respondents (n = 41, 62.1%) specified that they work in the public health system only.

3.3. Inclusion of a specialist nurse within the treatment team

Treatment team participants were asked to identify if there was currently a specialist nurse employed within their team to care for women with gynaecological cancers. Of the 66 treatment team members who responded to this question, 47 had a specialist nurse working within their team and 19 did not. Thirty one participants (66%) who worked with a specialist nurse worked in the public system.

3.4. Key aspects of specialist nurse role as identified by treatment team members

Participants identifying themselves as members of a multidisciplinary team which included a specialist nurse were asked to identify what they thought were the key aspects and benefits of the specialist nurse role. The responses of 47 participants were coded to minor categories from which five main categories were derived –

Table 1
Role in team according to country of work.

		Country of work		Total
		Australia	New Zealand	
Nurse Practitioner	Count	2	0	2
	% of Total	3.0%	0.0%	3.0%
Cancer Service Coordinator	Count	8	0	8
	% of Total	12.1%	0.0%	12.1%
Nurse Unit Manager	Count	4	0	4
	% of Total	6.1%	0.0%	6.1%
Nurse Educator	Count	4	0	4
	% of Total	6.1%	0.0%	6.1%
Registered Nurse	Count	13	0	13
	% of Total	19.7%	0.0%	19.7%
Gynaecological Oncologist/Fellow/Registrar	Count	6	2	8
	% of Total	9.1%	3.0%	12.1%
Gynaecologist/Registrar/Fellow	Count	3	0	3
	% of Total	4.5%	0.0%	4.5%
Medical Oncologist/Registrar/Fellow	Count	9	3	12
	% of Total	13.6%	4.5%	18.2%
Radiation Oncologist	Count	3	0	3
	% of Total	4.5%	0.0%	4.5%
Social Worker	Count	1	0	1
	% of Total	1.5%	0.0%	1.5%
Dietician	Count	1	0	1
	% of Total	1.5%	0.0%	1.5%
Psychologist	Count	3	0	3
	% of Total	4.5%	0.0%	4.5%
Research-related role	Count	3	1	4
	% of Total	4.5%	1.5%	6.1%
Total	Count	60	6	66
	% of Total	90.9%	9.1%	100.0%

Table 2
Geographical location of work according to country.

		Country of work		Total
		Australia	New Zealand	
Geographical location of work	Metropolitan	40	3	43
	Regional	14	2	16
	Metropolitan & Regional	3	1	4
	Rural	3	0	3
Total		60	6	66

Contact, communication, and coordination; Support and advocacy; Knowledge and education; Assessment, referral and management. The results are presented in Table 4 – key aspects of the gynaecological oncology specialist nurse role as identified by multidisciplinary team members.

3.4.1. Contact, communication and coordination

Specialist nurses were identified as providing a key point of contact in the healthcare system for women with gynaecological cancer and a central contact within the multidisciplinary team. Participants recognised that gynaecological cancer care was complex and the appointment of a single point of contact for women and their families was important to navigate them through the system. Likewise, the specialist nurse was identified as a central contact within the multidisciplinary team able to facilitate communication between the many specialists involved in the care of women with gynaecological cancers. Participants indicated that the specialist nurse was well suited as the central point of contact for the patient due to better availability and accessibility. Communication and liaison were also highlighted as key aspects of the specialist nurse role in gynaecological oncology.

Table 3
Sector of work.

		Sectors of healthcare system of work						Total	
		Public	Public and Private	Public and profit	Private Not-for-profit	Public and University	Private		Private not-for-profit
Role in team	Nurse Practitioner	1	0	0	0	0	0	1	2
	Cancer Service Coordinator	7	0	0	0	0	0	1	8
	Nurse Unit Manager	1	1	0	0	0	2	0	4
	Nurse Educator	3	0	0	0	0	1	0	4
	Registered Nurse	9	0	0	0	0	0	4	13
	Gynaecological Oncologist/Fellow/Registrar	3	4	0	0	0	1	0	8
	Gynaecologist/Registrar/Fellow	1	0	0	0	0	1	1	3
	Medical Oncologist/Registrar/Fellow	8	4	0	0	0	0	0	12
	Radiation Oncologist	3	0	0	0	0	0	0	3
	Social Worker	1	0	0	0	0	0	0	1
	Dietician	1	0	0	0	0	0	0	1
	Psychologist	1	2	0	0	0	0	0	3
	Research-related role	2	0	1	1	1	0	0	4
Total		41	11	1	1	1	5	7	66

Specialist nurses were identified as conduits of communication between members of the multidisciplinary team, between the multidisciplinary team and primary care providers, and between the multidisciplinary team and the woman. The role of the specialist nurse as ‘communicator’ was particularly valued by multidisciplinary team members when services were geographically disparate. A key aspect of the specialist nurse role identified by multidisciplinary team members was that of care coordination. The breadth of this task was determined by the area serviced by the multidisciplinary team. Participant examples of the role that specialist nurses play in contact, communication and coordination are provided in Table 4.

3.4.2. Support and advocacy

The provision of support and advocacy to women with gynaecological cancer and their families were identified as key aspects of the specialist nurse role. Participants perceived that the specialist nurse had more time to spend with the patient and were able to develop a close and therapeutic relationship with the woman. It was recognised that this enabled the specialist nurse to better understand the needs of the woman and play the role of patient advocate within the multidisciplinary team and the organisation. The role of the specialist nurse as advocate for the woman within multidisciplinary team meetings was highlighted by several participants with examples provided in Table 4.

3.4.3. Knowledge and education

Multidisciplinary team members highlighted the knowledge, skills, attributes and experience displayed by specialist nurses in the fulfilment of their role. Participants recognised that the specialist nurse requires expert knowledge and significant experience in gynaecological oncology to fulfil their role. Specialist nurses were identified as playing a key role in the provision of education and information to women and their families. The provision of education and information to women and their families was seen as complimentary to that offered by medical specialists. Participants also highlighted the role that specialist nurses played in the professional development of other team members. It was evident that in some services the specialist nurses remained the ‘constant’ and a source of information for doctors rotating through the service. Participant examples are provided in Table 4.

3.4.4. Assessment, referral and management

The processes of assessment, referral and management were among the specialist nurses’ responsibilities identified by participants. The specialist nurse was responsible for identifying the needs of the patient and referring the patient to appropriate health professionals either within or beyond the treatment team. The management of symptoms of

disease and side-effects of treatment were identified by participants as key aspects of the specialist nurse role with participant examples provided in Table 4.

Importance of specialist nurse involvement at given stages of the gynaecological cancer disease trajectory according to treatment team members

Treatment team members were asked to specify the importance of the involvement of a specialist nurse in the care of women at given points on their disease trajectory. Of the total 46 participants who responded to this question, the vast majority identified that the specialist nurse should be involved in the woman’s care at all stages along the disease trajectory with the most important time identified as during disease recurrence. Around one third of participants expressed that it was only somewhat important for the specialist nurse to be involved in the woman’s care when receiving chemotherapy or radiotherapy as they had other expert nurses available to them at this time.

3.5. Role overlap between treatment team members and specialist nurses

Participants were asked to identify if they had ever experienced role overlap with their specialist nurse and if so how they managed this. Thirty-eight participants responded to this question with 16 (42%) stating that they had not experienced role overlap with the specialist nurse. Most participants who identified that they had experienced role overlap with the specialist nurse saw this positively and described it as an opportunity to work as a team.

“Main overlap is dilator education, but this helped when I was on maternity leave as our CNC was able to provide dilator education in my absence and refer on for psychological concerns associated with it. We work closely and co-facilitate the gynae-onc support group.” – Psychologist SP-38

Some participants identified the need for better role definition and clear job descriptions for the specialist nurses that they worked with.

“Defining roles and rediscussing responsibility framework when this happens. Clear job description.” – Gynaecological oncologist SP-04

“There is definitely communication overlap at times - too many involved in the same conversation or specialist nurses contacting me to do things that have already been done” – Medical oncologist SP-08

“No clearly defined and respected roles” – Medical oncologist SP-28

Table 4
Key aspects of gynaecological specialist nurse identified by multidisciplinary team members.

Major category	Minor category	Participant example
Contact, communication and coordination	Key contact	“Single point of contact for patient and clinicians” – Gynaecological oncologist SP-20 “She is a central person within the gynaecological oncology team and facilitates patient care throughout the experience.” – Psychologist SP-38
	Availability	“Availability. More time to spend with patient and potentially better access” – Gynaecological oncologist SP-05 “... the ability to easily contact and seek information, support and care from an experienced specialist nurse is extremely beneficial for the women.” – Psychologist SP-25
	Communication	“Treatment team can involve up to 40 individuals and unit specialist nurse needs to understand and facilitate team function to ensure smooth transition of individual patient throughout trajectory.” – Radiation oncologist SP-09 “Link between primary and secondary care” – Gynaecological oncologist SP-10 “Ability to liaise between ‘Patient land’ and ‘Dr land’” – Psychologist SP-25 “Our nurse is the glue for our team” – Medical oncologist SP-02
	Geographically disparate services	“Significant [benefit]. Our gynae nurse is invaluable in helping us all work together. Especially as our surgeons are from out of town and do a weekly clinic at a different location in our hospital once a week. Our MDM is also video conferenced so there is a lot of organising to get info sent to [name of city] to be ready for meeting.” – Medical oncologist SP-27
	Care coordination	“Liaising with outpatients who have to attend three different centres for treatment” – RN SP-40 “Providing help in linking between the sub-specialities and also someone who is available to answer questions or help arrange things when the pt [patient] doesn't know how. Someone that knows the system and how to work through it.” – Medical oncologist SP-27 “Signposting where to go and what to do to navigate the health minefield” – Cancer service coordinator SP-42 “Our unit services the whole state and our nurse coordinates clinics, contacts patients, conveys information between team members, runs follow-up nurse led clinics to highlight survivorship issues and detect ongoing toxicities, runs gynae onc patient support groups” – Medical oncologist SP-28
	Support and advocacy	Support
Advocacy		“... I can think of repeated occasions at MDT where information directly relevant to patient care was offered by the specialist nurse and was missed by the treating specialist.” – Gynaecological oncologist SP-14 “Our nurse keeps the multidisciplinary team involved and is proactive in new strategies to improve patient experience” – Medical oncologist SP-02
Knowledge and education	Knowledge	“Expert knowledge gained from a “critical mass” of experience with women who have gynaecological cancer” – Social worker SP-64 “An understanding of the anatomy and function of the female reproductive organs; knowledge of disease types and their likely behaviour as well as evidence based managements and sequencing; familiarity with treatment modalities their immediate and delayed toxicities/side effects and their prevention or management; awareness of psychosocial needs and issues screening tools and resources available to support patients; training in interview technique to enable direct and referred support services ...” – Radiation oncologist SP-09
	Patient education	“Someone who has time to answer questions and clarify the doctor speak & demystify the jargon” – Cancer service coordinator SP-42 “The nurse saves my time in that after the consultations, she can provide complementary discussions and explanations regarding the reasons for treatments, side effects and what to expect.” – Radiation oncologist SP-21
	Professional development of other staff	“Supports and mentors new treatment team members to ensure uniformity of care. A ‘go to’ person for clarification and advice. Education in specialist service.” – Cancer service coordinator SP-37 “There is a wealth of knowledge and experience that can be tapped into by registrars and pelvic fellows by having a dedicated gynaecological oncology CNC as part of the team.” – Psychologist SP-38
Assessment, referral and management	Assessment and referral	“Ability of the nurse to identify, assess and respond to the unique needs of these women: including appropriate referral to other disciplines or services” – Social worker SP-64 “Support and triage about psycho-social concerns” – Psychologist SP-54
	Symptom and side effect management	“Management, in consultation with surgeon, of minor post-operative complications, eg minor wound issues, constipation, minor infections. Treating of patients post op problems” – Gynaecological oncologist SP-05 “Focus on good symptom control and monitoring of longer term toxicities” – Medical oncologist SP-28 “Reliable follow-up of symptoms in between medical appointments” – Medical oncologist SP-28

3.6. Concerns and disadvantages

Participants with a specialist nurse in their team were largely supportive of the gynaecological oncology specialist nurse role however some participants did express concerns and disadvantages relating to the role. Participants cautioned against the development of dependence on the specialist nurse. They identified that team members can become dependent on the specialist nurse, allowing them to not fulfil their role within the team. Likewise, the specialist nurse may complete tasks that the patient should do for themselves and not encourage self-management. Concerns about the specialist nurses' workload, and the need for

self-care and support, were also identified by participants. It was highlighted by some multidisciplinary team members that a large amount of the specialist nurses' time is spent on administrative tasks or filling service gaps. Nurses in other roles offered more critical perspectives of the gynaecological oncology specialist nurse role and indicated that ward staff may be more involved in the woman's care, and also have the necessary knowledge and experience to assist the woman. The importance of the specialist nurse's relationship with the woman and ward staff was also highlighted.

Concerns and disadvantages were coded to four main categories: Development of dependence; Workload and self-care; Administration

Table 5
Concerns and disadvantages of the gynaecological oncology specialist nurse role.

Category	Participant example
Development of dependence	<p>“Can take on too much responsibility. Can become more important than the role. Allows other team members to not fulfil their roles.” – Gynaecological oncologist SP-10</p> <p>“The patients can become dependent and not take responsibility for themselves”. – Medical oncologist SP-27</p> <p>“Disadvantage - maybe dependence - but a specialist nurse should be able to foster independence skills and behaviours or be able to refer to support people who could foster these skills.” – Cancer service coordinator SP-63</p>
Workload and self-care	<p>“Many referrals and may not be able to provide the tailored care that is necessary” – Cancer service coordinator SP 57</p> <p>“The only disadvantage I see is for the nurse specialist herself as the demands on her experience and expertise mean that she becomes the “problem solver” and “person who knows everything” and this has a high personal burden at times. People don't publicly acknowledge her awesomeness and the vital role that she plays” – Psychologist SP-25</p>
Administration and gap-filling	<p>“I think it can be an emotionally loaded job for the nursing staff and it is key to have self-care as part of the role.” – Medical oncologist SP-02</p> <p>“The role of the nurse care co-ordinator is invaluable! Unfortunately though, a large part of her time is taken up with administrative duties (eg retrieving forms to request tests, burning images to discs, ensuring appropriate scheduling of appointments) ... Our nurse care co-ordinators can end up compensating for deficiencies in the service generally - eg admin, social work, long wait for public hospital imaging etc.” – Radiation oncologist SP-21</p> <p>“I work closely with our specialist gynae nurse, so she is often helping me do things to make my life easier eg arranging tests, booking appts where pt [patient] can't, arranging apt [appointments] with other specialists. If she didn't help, then more would fall to me to do.” – Medical oncologist SP-27</p>
Role of other nurses	<p>“The nurse isn't directly involved in their day to day care.” - RN (chemotherapy) SP-60</p> <p>“[Patients] sometimes they feel that only the specialist nurse can help whilst often the ward staff have more experience/knowledge” - RN (Ward) SP-40</p> <p>“The only disadvantage I can see is if that specialist nurse doesn't form a good relationship with either the patient or ward nurses to create respect and open communication to assist the patient. This might be because of personality clashes or her unwillingness to engage” - Nurse educator SP-39</p>

and gap filling; Role of other nurses. These categories and corresponding participant examples are provided in Table 5 – Concerns and disadvantages of the gynaecological oncology specialist nurse role.

Perceptions of those who do not have a specialist nurse in their team

Of the 19 participants who did not have a specialist nurse in their team, 18 provided further comment on whether they thought a specialist nurse could make a contribution to their team and to women in their care. Three participants, a community cancer support nurse, a cancer service coordinator and a nurse manager indicated that a specialist nurse would not be of value to their team. The nurse manager was from a rural setting and did not elaborate on this further however the other two nurses indicated that a lack of patient numbers, and sufficient skill and experience among the existing nursing team, were their reasons for this.

“Live in a small rural town of 15000 people. I am the community cancer support nurse and we have a chemo nurse and a McGrath BC Nurse ... Would not be warranted here in our small community” – Community cancer support nurse SP-58

“All nurses on our team are experienced oncology nurses - our role is mainly counselling and providing information and support ... A specialist nurse is not necessary ...” – Cancer service coordinator SP-32

Other participants discussed how they believed a specialist nurse would contribute to their service.

“Yes - just look at how successful the McGrath model [McGrath Breast Cancer Nurses] of care has been to Breast patients - and they follow them through to palliative care so it's not just about the upfront treatments” – Medical oncologist SP-11

“Yes. We treat women with cancer in our large rural hospital. The debulking and brachytherapy occurs in [name of city] then patients continue chemotherapy under our oncologists. Unfortunately, these women [do] not have a tumour stream care coordinator at our hospital and so the communication on discharge from [name of city] is poor. We have tumour stream coordinators in lung, breast, prostate, upper GI and head and neck and haematology, but unfortunately due to funding restraints women with gynaecological cancers do not receive the appropriate level of support.” – Nurse Manager SP-44

4. Discussion

This study aimed to determine multidisciplinary team members' experiences and perceptions of the gynaecological oncology specialist

nurse role. Largely, multidisciplinary team members who worked with a specialist nurse valued their contribution to both the team and the care of women with a gynaecological cancer. Concerns and disadvantages relating to the role identified by team members included the development of dependence on the specialist nurse, the impact of large workloads, and the oversight of what other nurses can offer the patient. Most multidisciplinary team members without a specialist nurse in their team felt that they would make a valuable contribution to the team and the woman's care. However, some nurses from small or rural health services felt that they were able to meet the needs of the women in their care.

This study was part of a larger project aimed at describing and defining the role of specialist nurses in the provision of gynaecological cancer care in Australia and New Zealand. This study has contributed the perspective of a key stakeholder, the multidisciplinary team, to our understanding of the role. Multidisciplinary team members identified four key areas through which the specialist nurse contributes to the care of women with gynaecological cancers: contact, communication and coordination; support and advocacy; knowledge and education; assessment referral and management. These domains of care should be used in conjunction with the perspectives of other key stakeholders to develop a formal definition of the role and inform guidelines for practice. Multidisciplinary team members highlighted that a key aspect of the specialist nurse role was offering a point of ‘central contact’ for women with gynaecological cancer within the healthcare system. The majority of participants in this study believed that it was important for a specialist nurse to be involved in the care of women with a gynaecological cancer across all stages of the disease trajectory. Continuity, and knowing the patient and their family well, have been identified as important parts of serving as the woman's central contact, allowing the woman to have her concerns addressed without having to provide lengthy explanations of her history (Fincham et al., 2005; Kobleider et al., 2017; Walsh et al., 2011).

Just as the participants identified the specialist nurse as a central contact for the woman, they also played a significant role in the communication of the team. A gynaecological oncologist in this study expressed that their specialist nurse was the ‘glue for their team’. Effective communication is required, both between professionals within the multidisciplinary team to ensure timely and complete care, and between the multidisciplinary team and the patients themselves. A study by Lawn et al. (2017) found that cancer patients felt burdened when they had to take responsibility for information sharing and communication processes between health professionals and services. Participants in the study recognised the benefits of a key contact who acted as

a bridge between health professionals and services (Lawn et al., 2017). Navigation of complex healthcare without support can lead to patients ‘falling through the gaps’ when communication between health professionals is poor or communication of the treatment plan with patients is poor (Walsh et al., 2011). Multidisciplinary team members in this study identified that specialist nurses were responsible for ensuring that patients transitioned smoothly between episodes of care, departments or health care settings.

Caution must however be exercised when using these communication and coordination aspects of the role to ‘define’ it. The potential for women and the multidisciplinary team to become over-dependent on the specialist nurse was an area of concern for some participants in this study. A small Australian study found that cancer care coordinators (specialist nurses) identified their role as “everything to everyone” and recognised the potential for deskilling of patients and team members when they completed tasks that the patient or multidisciplinary team could do for themselves (Regan et al., 2012). Thus, whilst dependability is the hallmark of the specialist nurse role, over-dependence could be detrimental to women, the team and the specialist nurse themselves. The *Clinical Oncology Society of Australia* (2015) advise that care coordination should be the responsibility of the entire multidisciplinary team. Whilst women value having a key contact, knowledge and information sharing among the team must be sufficient that the care and safety of the woman would not be compromised in the absence of the specialist nurse. The health and safety of the specialist nurse could also be compromised if they feel they are not able to take leave due to care and coordination being too heavily reliant on them as an individual. To prevent over-dependence, the specialist nurse role must be part of a system, not the system itself.

There is a need to ensure that specialist nurse workloads are manageable, nursing-focused, and do not encourage over-dependence. Participants in this study noted that their specialist nurses fulfilled administrative roles and compensated for deficiencies in other services such as social work. The *Clinical Oncology Society of Australia* (2015) recommended that cancer care coordination is distinguished from administrative roles and that administrative support should be available to coordinators of cancer care. Completion of administrative tasks was identified in other studies as an aspect of specialist nurse roles which took the specialist nurses away from providing skilled care (Cumming, 2012; Leary et al., 2016; Leary et al., 2014; Taylor et al., 2018). Leary et al. (2016) reported that overtime levels were lowest for Clinical Nurses Specialists with administrative support.

A greater emphasis on the role rather than the individual is thus required. Where bespoke roles have developed around individual nurses, a more standardised approach is now needed. Consistent nomenclature, clearly identifiable education and career pathways for other nurses to prepare for the role, and clear guidelines for practice within the role, all shift the emphasis away from the individual ‘as’ the role.

5. Limitations and future directions

This study was limited by the method of data collection. It is acknowledged that in a qualitative study, ‘written’ responses limit the researcher’s ability to clarify meaning or prompt elaboration from the participant, thus restricting the depth of inquiry and understanding that can be gained from this method of data collection. Although snowballing was used as a recruitment method in this study, the primary recruitment of participants from two professional bodies may have led to the exclusion of non-members from this study and biased the sample towards those more interested in professional issues. As the survey was completed anonymously and data on recruitment source were not captured, it was not possible to determine which organisation each participant was associated with nor the response rate from each organisation. Recruitment from New Zealand was highly reliant on the snowballing method and in hindsight a more direct recruiting strategy

may have resulted in a larger number of New Zealand participants, especially nursing and allied health professionals.

Although nurses made up over one third of the sample this is not disproportionate to the number of nurses who would make up a treatment team. Where it could be expected that nurses would naturally offer support for a nursing role, the nurses in this study brought a more critical and balanced perspective on the specialist nurse role than those from a medical or allied health background.

Although this study was about the care of women with gynaecological cancers by female gynaecological nurses, gender issues relating to their roles and responsibilities were not analysed. It is acknowledged that a feminist methodology would have resulted in a different interpretation of the results and perspective of the role.

This research has highlighted the need for specialist nurse roles to be more clearly defined in the future. The insights gained through this study, in conjunction with those from the women and specialist nurses themselves, must inform the development of a model of specialist nursing care for women with gynaecological cancers within the Australian and New Zealand health care contexts. Standardised nomenclature and guidelines for practice based on the key aspects of the role identified in this study, are recommended to ensure that the specialist nurse role and their scope of practice are clear to key stakeholders and over-dependence on the individual in the role is mitigated. Equity of access to specialist nursing care for women with gynaecological cancer should also be ensured as many participants in this study did not have a specialist nurse working in their team and many saw this as a disadvantage to the women they cared for. Multidisciplinary team members expressed that it was important for a specialist nurse to be involved in a woman’s care across the disease trajectory and health care services, including private health care providers, should prioritise this service.

6. Conclusions

Multidisciplinary team members identified that specialist nurses play the role of ‘central contact’ for patients and their families and offered continuity and support throughout their cancer journey. Participants highlighted the role that specialist nurses played in the provision of education, information, assessment, referrals and advocacy for women with gynaecological cancers. Team members utilised specialist nurses as conduits for communication between members of the team and between the patient and the team. However, multidisciplinary team members cautioned against the development of over-dependence on the specialist nurse by team members and women in their care. Participants without a specialist nurse in their team believed that this was a disadvantage to the women in their care except where other experienced and skilled nurses were able to fill this void. This study has contributed the perspective of a key stakeholder, the multidisciplinary team, to our understanding of the gynaecological oncology specialist nurse role.

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References

- Cancer Australia & The Royal Australian College of Obstetricians and Gynaecologists, 2011. National Gynaecological Cancer Service Delivery and Resource Framework. Cancer Australia, Canberra, Australia.
- Carlsson, M.E., Strang, P.M., 1998. Educational support programme for gynaecological cancer patients and their families. *Acta Oncol.* (Stockholm, Sweden) 37 (3), 269–275.
- Clinical Oncology Society of Australia, 2015. *Cancer Care Coordinator Position Statement*. Sydney.
- Cook, McIntyre, M., Recoche, K., 2015. Exploration of the role of specialist nurses in the

- care of women with gynaecological cancer: a systematic review. *J. Clin. Nurs.* 24 (5/6), 683–695. <https://doi.org/10.1111/jocn.12675>.
- Cook, O., McIntyre, M., Recoche, K., Lee, S., 2017. Experiences of gynecological cancer patients receiving care from specialist nurses: a qualitative systematic review. *JBIS Database System. Rev. Implementat. Rep.* 15 (8), 2087–2112. <https://doi.org/10.11124/JBISRIR-2016-003126>.
- Cumming, G., 2012. Survey looks at issues facing clinical nurse specialists. *Kai Tiaki Nursing N. Z.* 18 (5), 26–28.
- Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., Kyngäs, H., 2014. Qualitative Content Analysis. vol. 4 SAGE Open <https://doi.org/10.1177/2158244014522633>. 1.
- Fincham, L., Copp, G., Caldwell, K., Jones, L., Tookman, A., 2005. Supportive care: experiences of cancer patients. *Eur. J. Oncol. Nurs.* 9 (3), 258–268. <https://doi.org/10.1016/j.ejon.2004.08.004>.
- Fung-Kee-Fung, M., Kennedy, E.B., Biagi, J., Colgan, T., D'Souza, D., Elit, L.M., et al., 2015. An organizational guideline for gynecologic oncology services. *Int. J. Gynecol. Cancer* 25 (4), 551–558. <https://doi.org/10.1097/igc.0000000000000400>.
- Jefferies, H., 2002. Ovarian cancer patients: are their informational and emotional needs being met? *J. Clin. Nurs.* 11 (1), 41–47. <https://doi.org/10.1046/j.1365-2702.2002.00570.x>.
- Kobleder, A., Mayer, H., Gehrig, L., Senn, B., 2017. “Promoting continuity of care”—specialist nurses’ role experiences in gynaecological oncology: a qualitative study. *J. Clin. Nurs.* 26 (23–24), 4890–4898. <https://doi.org/10.1111/jocn.13966>.
- Kruss, G., Macindoe, J., Davis, H., 2014. Specialist Metastatic Breast Care Nurse Melbourne. Southern Melbourne Integrated Cancer Service.
- Lawn, S., Fallon-Ferguson, J., Koczwara, B., 2017. Shared care involving cancer specialists and primary care providers - what do cancer survivors want? *Health Expect.* 20 (5), 1081–1087. <https://doi.org/10.1111/hex.12551>.
- Leary, A., Brocksom, J., Endacott, R., Fleure, L., Howdle, F., Masterton, M., et al., 2016. The specialist nursing workforce caring for men with prostate cancer in the UK. *Intern J Urolog Nurs* 10 (1), 5–13. <https://doi.org/10.1111/ijun.12104>.
- Leary, A., White, J., Yarnell, L., 2014. The work left undone. Understanding the challenge of providing holistic lung cancer nursing care in the UK. *Eur. J. Oncol. Nurs.* 18 (1), 23–28. <https://doi.org/10.1016/j.ejon.2013.10.002>.
- Maughan, K., Clarke, C., 2001. The effect of a clinical nurse specialist in gynaecological oncology on quality of life and sexuality. *J. Clin. Nurs.* 10 (2), 221–229. <https://doi.org/10.1046/j.1365-2702.2001.00465.x>.
- National Gynaecological Cancer Tumour Standards Working Group, 2013. Standards of Service Provision for Gynaecological Cancer Patients in New Zealand. New Zealand Ministry of Health, Wellington.
- NHS Commissioning Board, 2013. NHS Contract for Complex Gynaecology-Specialist Gynaecological Cancers. Service Specifications. NHS Commissioning Board.
- Polit, D., Beck, C., 2010. *Essentials of Nursing Research : Appraising Evidence for Nursing Practice*, seventh ed. ed. Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins, Philadelphia.
- Qualtrics LLC, 2015. Qualtrics. Qualtrics, Provo, Utah Retrieved from. <https://www.qualtrics.com/>.
- Regan, M., Mills, J., Risteovski, E., 2012. Cancer care coordinators’ relationships with the multidisciplinary team and patients: everything to everyone. *Austral. J. Canc. Nurs.* 13 (1), 12–19.
- Roberts, J., Floyd, S., Thompson, S., 2011. The clinical nurse specialist in New Zealand: how is the role defined? *Nurs. Prax. N. Z.* 27 (2), 24.
- Taylor, K., Monterosso, L., Bulsara, C., 2018. Qualitative results from a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. *Eur. J. Oncol. Nurs.* 35, 9–14. <https://doi.org/10.1016/j.ejon.2018.01.011>.
- The National Breast Cancer Centre, 2000. Specialist Breast Nurses: an Evidence-Based Model for Australian Practice. National Breast Cancer Centre, Kings Cross, NSW.
- The National Breast Cancer Centre, 2005. Specialist Breast Nurse Competency Standards and Associated Educational Requirements. The National Breast Cancer Centre, Camperdown, Australia.
- Thorne, S.E., 2016. *Interpretive Description : Qualitative Research for Applied Practice*. Routledge, London.
- Walsh, J., Young, J.M., Harrison, J.D., Butow, P.N., Solomon, M.J., Masya, L., White, K., 2011. What is important in cancer care coordination? A qualitative investigation. *Eur. J. Cancer Care* 20 (2), 220–227. <https://doi.org/10.1111/j.1365-2354.2010.01187.x>.