MONASH University

Describing and defining the role of specialist nurses in the provision of gynaecological cancer care in Australia and New Zealand

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Bachelor of Nursing (Hons)

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Abstract

Aim: This study aimed to describe and define the specialist nurse role in the provision of gynaecological oncology cancer care in Australia and New Zealand. This study sought the perspectives of specialist nurses and members of the gynaecological oncology workforce to determine the contribution of specialist nurses to gynaecological cancer care now and into the future.

Background: In developed nations, where comprehensive cancer treatment and care is mostly available, women with gynaecological cancers may have access to specialist nursing care. The gynaecological oncology specialist nurse role has emerged over the past 20 years along with other tumour-specific cancer specialist nurse roles. However, the role has developed without direction in Australia and New Zealand resulting in disparity in practice within and between jurisdictions.

Methodology: Interpretive Description was chosen as the methodological approach for this qualitative study based on its aim to generate new knowledge for nursing practice. Two main participant groups, gynaecological oncology specialist nurses and other members of gynaecological oncology multidisciplinary teams, were recruited to the study through two professional bodies. Three data collection methods were employed: individual interviews, focus groups and an online survey. Data were subjected to one of three analysis methods including descriptive statistics, inductive content analysis, and thematic analysis. The major findings of each data set were conceptualised in a model.

Results: One hundred and two participants responded to the online survey and nineteen specialist nurses contributed to interview and focus groups. Specialist nurses played the role of 'central contact' for women with gynaecological cancers and their families and offered continuity and support throughout their cancer journey. Key aspects of the specialist nurse role identified were: information and education provision; care coordination; assessment; referral; clinical expertise; advocacy; administration. Differences in the execution of the role were identified between specialist nurses and organisations. Participants without a specialist nurse in their team believed that women with gynaecological cancers were disadvantaged by

not having access to a specialist nurse. Four major themes were derived from the specialist nurses' experiences and perceptions of their role: 'Working between worlds'; 'The patient's go-to person'; 'When so much depends on one person'; 'A clearer pathway.

Discussion: A model conceptualising specialist nurses as the 'keystone' of gynaecological cancer care in Australia and New Zealand was postulated. The model identified the major aspects of the specialist nurse role along with threats to the stability of the role including a lack of professional support and poor role definition. The specialist nurses in this study were trailblazers in their field though many perceived a lack of recognition of their role from the nursing profession.

Conclusion: Specialist nurses play a key role in the provision of gynaecological cancer care across Australia and New Zealand. Members of gynaecological oncology multidisciplinary teams were highly supportive of the specialist nurse role. Gynaecological oncology specialist nurses have evolved their role over time to meet the changing needs of their healthcare organisations resulting in variation in the role between nurses.

Recommendations: Guidelines for practice across the disease trajectory, standardisation of nomenclature, the development of education and career pathways, and the evaluation of specialist nursing roles are all required to further define the specialist nurse role in gynaecological oncology. Access to specialist nursing care is recommended for all women with gynaecological cancers.

Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

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Date: May 3, 2018

Publications during enrolment

Cook, O., McIntyre, M., & Recoche, K. (2015). Exploration of the role of specialist nurses in the care of women with gynaecological cancer: a systematic review. *Journal Of Clinical Nursing, 24*(5/6), 683-695. doi:10.1111/jocn.12675

Cook, O., McIntyre, M., Lee, S., & Recoche, K. (2015). The experiences of gynecological cancer patients who receive care from specialist nurses: a systematic review protocol. *JBI Database of Systematic Reviews & Implementation Reports* 13(8), 11, 135-145. doi:10.11124/jbisrir-2015-2271

Cook, O., McIntyre, M., Recoche, K., & Lee, S. (2017). Experiences of gynecological cancer patients receiving care from specialist nurses: a qualitative systematic review. *JBI Database of Systematic Reviews & Implementation Reports, 15*(8), 2087-2112. doi:10.11124/JBISRIR-2016-003126

Thesis including published works declaration

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes one original paper published in a peer reviewed journal and one submitted publication. The core theme of the thesis is the specialist nursing care of women with gynaecological cancers. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within Monash Nursing and Midwifery under the supervision of Associate Professor Meredith McIntyre.

Thesis Chapter	**Publication Title**	**Status** *(published, in press, accepted or returned for revision, submitted)*	**Nature and % of student contribution**	**Co-author name(s) Nature and % of Co-author's contribution***	**Co-author(s), Monash student Y/N***
2	Experiences of gynecological cancer patients receiving care from specialist nurses: a qualitative systematic review.	Published	70% devised protocol, wrote background, first reviewer of all papers, data extraction, drafted report.	Meredith McIntyre – Second reviewer of papers, data extraction, review of draft paper 10% Katrina Recoche – Third reviewer of papers, review of draft, 10% Susan Lee – Second reviewer of papers, data extraction, review of draft paper, 10%	No
3	The needs of women with gynaecological cancer across their disease trajectory: an integrative review.	Under review	75% devised protocol, wrote background, first reviewer of all papers, data extraction, drafted report.	Meredith McIntyre – Second reviewer of papers, audit of data extraction, review of draft paper 15% Susan Lee – Second reviewer of papers, review of draft paper, 10%	No

I have not renumbered sections of submitted or published papers in order to generate a consistent presentation within the thesis.

Student signature: [redacted] **Date:** 03.05.2018

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the student's and co-authors' contributions to this work. In instances where I am not the responsible author I have consulted with the responsible author to agree on the respective contributions of the authors.

Main Supervisor signature: [redacted] **Date:** 03.05.2018

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I would like to thank the amazing health care professionals, especially the specialist nurses, who participated in this study. Thank you for caring enough about this topic to take the time to participate. I am so grateful for your contribution and I hope that the results deliver the changes that you need to embed the specialist nursing role in gynaecological cancer care. Thank you also to the Cancer Nurses Society of Australia and the Australia and the New Zealand Gynaecological Oncology Group for their support in recruiting participants and advertising the study. An extra special thanks to Anne Mellon for her wonderful support before and during the study – what Anne does every day for women with gynaecological cancer, both directly and through her professional activities, is nothing short of remarkable.

Thank you to my family – my husband Steve, beautiful daughters Audrey and Annabel, Mum, Nan, George and the Hansons. What a journey this has been for all of us! You have given me your time and allowed me to do this and I am so very grateful. I simply couldn't have done it without you. I hope that you can all enjoy and share this achievement. I've been loved and supported my whole life, and this is as much your achievement as mine Mum, Dad and Nan.

Finally, I dedicate this thesis to my Dad, Christopher Cook, who left us in 2011 after living with cancer for 18 years. He did not have access to specialist nursing care during his battle with a rare lymphoma and his experience was a source of motivation for this study. It is my hope that this study contributes to the wider discussion on specialist cancer nursing and that all cancer patients have access to specialist nursing care in the future. Most of all I wish I could share this moment with the man who nurtured me and gave me the confidence to pursue my goals. I promise Dad I will take some time now to 'smell the roses'.

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Chapter 1- Introduction and Background

Gynaecological cancers affect hundreds of thousands of women every year across the world. Many women with gynaecological cancers do not have access to comprehensive treatment of their disease. Of those with access to treatment, many will not be cured and mortality rates for some gynaecological cancers are high in comparison to other cancer types. The needs of women with gynaecological cancer are significant and often unmet. This thesis considers the contribution of specialist nurses to the care of women with gynaecological cancer in Australia and New Zealand. An Interpretive Description approach was taken to describe and define the specialist nurse role in gynaecological oncology and gain the perspectives of key stakeholders on the role. This thesis identifies the issues and barriers encountered by specialist nurses in their provision of care to women with gynaecological cancers and outlines recommendations for the future of the role.

This chapter provides the background upon which the study was founded and details the aims of the project, research questions and a statement of significance of the study. The incidence, survival and mortality rates of gynaecological cancers in Australia and New Zealand are discussed in the worldwide context. The history and evolution of specialist nursing roles are also explored and more specifically the emergence of specialist cancer nursing and specialist gynaecological cancer nursing roles are discussed. This chapter also provides the background of the author as an 'insider researcher', forming the theoretical forestructure of this Interpretive Description study.

Background

Gynaecological cancers is a collective term referring to cancers of the female reproductive system including cancers of the ovary, cervix, uterus, vulva, vagina and fallopian tubes (Australian Institute of Health & Welfare & Cancer Australia, 2012). Global data do not exist on all gynaecological cancers though it is known that cervical, uterine and ovarian cancer together account for approximately 17 per cent of world cancer incidence in women (Ferlay et al., 2015). However, marked differences exist in the incidence of these cancers between developed and developing nations (Ferlay et al., 2015).

Gynaecological cancers: incidence, survival, mortality and risk

Cervical cancer

Cervical cancer in the fourth most common cancer affecting women in the world representing 7.9 per cent of new cancer cases, following breast cancer at 25.2 per cent, colorectal cancer at 9.2 per cent and lung cancer at 8.7 percent of new cancer cases (Ferlay et al., 2015). The large majority of global cervical cancer incidences, around 87 per cent, occur in less developed regions with it being the most common cancer in women in Eastern and Middle Africa (Ferlay et al., 2015). Age-standardised incidence rates for cervical cancer is highest in Eastern Africa affecting 42.7 women per 100,000 followed by rates of 33.3 per 100,000 in Melanesia, 31.5 per 100,000 in Southern Africa and 30.6 per 100,000 in Middle Africa. Comparatively, Australia and New Zealand have very low age-standardised cervical cancer incidence rates affecting 5.5 in every 100,000 women (Ferlay et al., 2015).

Cervical cancer is now a highly preventable disease most commonly caused by Human Papilloma Virus (HPV) infection. HPV strains 16 and 18 of the virus are responsible for 70-80 per cent of cervical cancers in Australia (Australian Institute of Health and Welfare, 2016). It is expected that national HPV vaccination programs in Australia and New Zealand introduced in 2007 and 2008 respectively, will further reduce the incidence of cervical cancer in the two countries (Australian Institute of Health and Welfare, 2016; New Zealand Ministry of Health, 2008). However, the incidence of cervical cancer is expected to rise further over the next 20 years in countries where the burden of disease is greatest and the capacity to vaccinate, screen and treat the disease is lowest (Ahmed et al., 2012; Denny et al., 2013). Control of communicable diseases such as malaria, tuberculosis and Human Immunodeficiency Virus (HIV) consume health-related funding in Sub-Saharan Africa where cytology-based screening programs such as those in Australia and New Zealand are considered cost-prohibitive (Denny et al., 2013; Elamin, Ibrahim, Abuidris, Mohamed, & Mohammed, 2015). Denny et al. (2013) identified the need for Sub-Saharan African countries to finance and implement an HPV vaccination program as the most cost-effective way of preventing cervical cancer in the region. A study mapping HPV vaccination and cervical cancer screening in the Pacific region, including Melanesia, found that only two of the 21 countries studied had achieved cervical cancer screening coverage of more than 40 per cent (Obel et al., 2015). Similarly, only two of the 21 countries studied had achieved HPV vaccination of over 60% of the target population, though 10 of these countries did include HPV vaccine in their immunisation schedules (Obel et al., 2015). Lack of sustainable financing for HPV vaccination programs was reported by the heads of health of participating countries as the main barrier to implementing such programs (Obel et al., 2015).

Although the cervical cancer rates of Australian and New Zealand women are low compared with the rest of the world, the Indigenous women of each country have significantly higher incidence and death rates

from the disease compared with their non-Indigenous counterparts (Australian Institute of Health & Welfare & Cancer Australia, 2012, 2013; Ministry of Health, 2016; New Zealand Ministry of Health, 2015). Likewise, five-year survival rates are lower for Indigenous women than non-Indigenous women with cervical cancer from both countries as shown in Table 1.1 (Australian Institute of Health & Welfare & Cancer Australia, 2012; New Zealand Ministry of Health, 2015). The risk factors for the development of cervical cancer are HPV infection, smoking, lack of screening, age, long term contraceptive pill use, previous cervical abnormality, multiparity and diethylstilboestrol exposure (DEH) (Cancer Australia, 2017a).

Table 1.1 Cervical Cancer rates in Australia and New Zealand

	Australia			New Zealand		
	Overall	**Indigenous**	**Non-Indigenous**	**Overall**	**Indigenous**	**Non-Indigenous**
Incidence	6.8 per 100,000 (2013)[#]	18.0 per 100,000 (2008)[#]	6.5 per 100,000 (2008)[#]	6.3 per 100,000 (2013)[#]	12.7 per 100,000 (2013)[#]	5.6 per 100,000 (2013)[#]
5 year survival rate	72%	51.2%	67%	73.7%	68.2%	75%
Deaths	1.7 per 100,000	7.1 per 100,000	1.8 per 100,000	1.7 per 100,000	4.0 per 100,000	1.4 per 100,000

[#]Data are most recently published for each measure, not all relating to same year

Ovarian cancer

Unlike cervical cancer, ovarian cancer is a disease mostly affecting women of developed nations. It is estimated that ovarian cancer accounts for 3.6 per cent of all cancers affecting women worldwide (Ferlay et al., 2015). The age-standardised incidence of ovarian cancer in less developed regions is 4.9 women per 100,000 compared with Central, Eastern and Northern Europe where rates of incidence are 14 per 100,000 or higher. Age-standardised incidence of ovarian cancer in Australia and New Zealand are currently 6.8 and 8.5 women per 100,000 respectively (Australian Institute of Health & Welfare, 2017; Ministry of Health, 2016). There is no significant difference in the incidence of ovarian cancer among the Indigenous and Non-Indigenous populations of Australia and New Zealand (Australian Institute of Health & Welfare & Cancer Australia, 2012; Ministry of Health, 2016).

Survival rates of women with ovarian cancer have improved over recent years though remain much lower than overall cancer survival rates in Australia. Five year survival rates for women with ovarian cancer in Australia and New Zealand are 43 per cent and 39 per cent respectively (Australian Institute of Health & Welfare & Cancer Australia, 2012; New Zealand Ministry of Health, 2015) compared with a national Australian 5 year cancer survival average of 68 percent (Australian Institute of Health & Welfare, 2017). Poor survival rates are attributed mainly to diagnosis of the disease in advanced stages in a majority of cases (Tracey et al., 2009). Diagnosis of ovarian cancer is made difficult by its vague symptoms such as abdominal bloating or pain, appetite loss, indigestion, urinary and bowel changes, unexplained weight loss or gain, and unexplained fatigue (Cancer Australia, 2017d). To date no definitive screening test exists for ovarian cancer (Cancer Australia, 2017d).

Mortality rates for ovarian cancer are slightly better in New Zealand than Australia with rates of 4.6 and 6.8 per 100,000 females respectively (Australian Institute of Health & Welfare, 2017; Ministry of Health, 2016). Risk factors for the development of ovarian cancer include a family history of ovarian, breast or colon cancer or a known gene mutation of the BRCA1 or BRCA2 genes or Lynch Syndrome (Australian Institute of Health & Welfare & Cancer Australia, 2012). Women also have an increased chance of developing ovarian cancer with increasing age, endometriosis, use of hormone replacement therapy, smoking and obesity (Australian Institute of Health & Welfare & Cancer Australia, 2012).

Endometrial cancer

Similar to ovarian cancer, endometrial or uterine cancer more commonly affect women from developed nations. Global incidence rates of endometrial cancer in more developed nations for 2012 were 14.7 per 100,000 women compared with 5.5 per 100,000 women in less developed nations (Ferlay et al., 2015). However data reported by both the Australian and New Zealand governments for the following year indicate that the incidence rates of endometrial or uterine cancer in these countries is 18.6 and 16.8 per 100,000 women respectively and rising steadily (Australian Institute of Health & Welfare, 2017; Ministry of Health, 2016). The rise in incidence of endometrial cancer may be attributable to growing obesity rates as it is a major risk factor for the development of endometrial or uterine cancer (Cancer Australia, 2015). Other risk factors include obesity with diabetes and high blood pressure; history of chronic anovulation or polycystic ovary syndrome (PCOS); treatment with oestrogen without progesterone therapy; tamoxifen use; familial endometrial, ovarian or colon cancer, or Lynch syndrome; nulliparity (Cancer Australia, 2015). As the body synthesises oestrogen in adipose tissue, the increased risk of obese women developing endometrial cancer may be attributable to higher levels of oestrogen (Cancer Australia, 2015).

As for cervical cancer, Indigenous women of Australia and Maori women of New Zealand are around one and a half times more likely than their non-Indigenous counterparts to develop endometrial cancer (Australian Institute of Health & Welfare & Cancer Australia, 2013; Ministry of Health, 2016). In Australia, Indigenous women are 2.4 times more likely to die from endometrial cancer than non-Indigenous women with mortality rates at 6.6 and 2.8 per 100,000 women respectively (Australian Institute of Health & Welfare & Cancer Australia, 2013). Maori women are 1.6 times more likely to die from endometrial cancer in New Zealand than non-Maori women (Ministry of Health, 2016).

Survival rates of women with endometrial cancer are significantly better than that of women with ovarian cancer. Australian women diagnosed with endometrial cancer have an 83 per cent chance of being alive five years after their diagnosis and this rate is lower at 78.4 per cent for women in New Zealand (Australian Institute of Health & Welfare, 2017; Ministry of Health, 2016). Mortality rates for women with endometrial cancer are 3.4 and 3.2 per 100,000 women in Australia and New Zealand respectively (Australian Institute of Health & Welfare, 2017; Ministry of Health, 2016). With a greater incidence of endometrial cancer in their populations, Indigenous women of Australia and New Zealand are 1.6 - 2.4 times more likely than their non-Indigenous counterparts to die from endometrial cancer (Australian Institute of Health & Welfare & Cancer Australia, 2013; Ministry of Health, 2016).

Vulval, vaginal and other gynaecological cancers

Global data are not available on the incidence, survival and mortality rates of the less common gynaecological cancers though some data are available for Australia and New Zealand. Cancer of the vulva

affects 2.3 per 100,000 women in Australia and 1.5 per 100,000 in New Zealand though the incidence rate in Maori women of New Zealand is 2.3 per 100,000 women (Australian Institute of Health & Welfare & Cancer Australia, 2012; Ministry of Health, 2016). All other cancers of the female reproductive system affect between 1.0-1.5 per 100,000 women in Australia and New Zealand (Australian Institute of Health & Welfare & Cancer Australia, 2012; Ministry of Health, 2016). Data on the incidence of vulval, vaginal and other uncommon gynaecological cancers are not available for Indigenous Australian women. The five-year survival rates for Australian women with vulval cancer are 71.3 per cent though Australian women with vaginal cancer have only a 45 per cent chance of survival five years beyond their diagnosis (Australian Institute of Health & Welfare & Cancer Australia, 2012). Risk factors for the development of vulval cancer include: precancerous conditions such as vulval intraepithelial neoplasia (VIN); skin conditions; smoking (Cancer Australia, 2017c). The known risk factors for the development of vaginal cancer are: diethylstilbestrol exposure (DES); human papillomavirus (HPV) infection; previous cervical cancer or pre-cervical cancer; previous radiotherapy to the pelvic area (Cancer Australia, 2017b).

Treatment and care provided to women with gynaecological cancers in Australia and New Zealand

Unlike many women in developing nations, most women with gynaecological cancers in Australia and New Zealand have access to comprehensive treatment of their cancer. The medical care provided to women with gynaecological cancers in the two nations are guided by evidence-based frameworks and clinical practice guidelines (Cancer Australia, 2011, 2014b, 2016; Cancer Australia & Royal Australian College of Obstetricians and Gynaecologists, 2011; Cancer Council Australia Endometrial Cancer Guidelines Working Party, 2014; National Gynaecological Cancer Tumour Standards Working Group, 2013; New Zealand Gynaecological Cancer Group, 2015). Optimal treatment and care involves 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 (including social workers, psychologists and physiotherapists), palliative care providers, sexual health counsellors, Aboriginal and Torres Strait Islander Health Workers, geneticists, dieticians, and genetic counsellors (Cancer Australia & Royal Australian College of Obstetricians and Gynaecologists, 2011; National Gynaecological Cancer Tumour Standards Working Group, 2013). Multidisciplinary team meetings should ideally consider cases prior to definitive treatment and cases may also need to be considered by the multidisciplinary team post-surgery, once histopathology results are available (National Gynaecological Cancer Tumour Standards Working Group, 2013).

Treatment of a gynaecological cancer is often multimodal, most commonly involving surgery followed by adjuvant chemotherapy and/or radiotherapy. Sometimes first-line chemotherapy and interval surgical debulking is utilised in the treatment of women with advanced ovarian cancer (National Gynaecological Cancer Tumour Standards Working Group, 2013). Women requiring radical surgery for their gynaecological cancer should be operated on by a gynaecological oncologist to ensure optimal outcomes, as planning and undertaking many gynaecologic cancer surgeries is beyond the scope of general training in Obstetrics and Gynaecology (Cancer Australia & Royal Australian College of Obstetricians and Gynaecologists, 2011; National Gynaecological Cancer Tumour Standards Working Group, 2013). In Australia, women with gynaecological cancers should have their surgical treatment completed at a centralised comprehensive gynaecological cancer treatment centre or by a visiting gynaecological oncologist to a smaller or regional cancer service (Cancer Australia & Royal Australian College of Obstetricians and Gynaecologists, 2011). Adjuvant therapies may then be provided more locally for women where available, except where external beam radiotherapy combined with brachytherapy is

required which is only available at larger centres in Australia (Cancer Australia & Royal Australian College of Obstetricians and Gynaecologists, 2011).

Post-treatment, women with gynaecological cancers commonly enter a documented follow-up plan aimed at identification and management of recurrent disease, the side effects of treatment, and the provision of psychosocial support (National Gynaecological Cancer Tumour Standards Working Group, 2013). Treating medical specialists, specialist nurses, referring gynaecologists and primary care providers may all be involved in the provision of follow-up care to women with a gynaecological cancer (National Gynaecological Cancer Tumour Standards Working Group, 2013). Common side effects of gynaecological cancer treatment include psychosocial morbidity, infertility, bladder dysfunction, vaginal stenosis, dyspareunia, sexual dysfunction, lymphoedema and bowel dysfunction (National Gynaecological Cancer Tumour Standards Working Group, 2013).

The provision of specialist nursing care to women with a gynaecological cancer is recommended in several gynaecological cancer guidelines in Australia and New Zealand. However, specific guidelines around the specialist nursing care of women with gynaecological cancers are lacking in Australia and New Zealand. Australian guidelines do not specify when or how often a woman with a gynaecological cancer should be seen by a specialist nurse or what care that specialist nurse should provide at each phase of the woman's journey. Currently, the practice of gynaecological oncology specialist nurses is determined and controlled by the nurses' employing organisation, without formal or standardised guidelines for practice in place.

Nursing specialisation – a brief history

Nurses have long 'specialised' in the many areas of nursing, however recognition of the clinical nurse specialist role commenced in the 1960s in the United States with the development of core practice competencies (Fulton, Lyon, & Goudreau, 2014). In 1980, the American Nurses Association stipulated that a clinical nurse specialist was an expert in a selected area of nursing through study and supervised practice at the Master's or Doctorate level (Fulton et al., 2014). Delineation and standardisation of advanced practice roles, including those of the clinical nurse specialist (CNS) and certified nurse practitioner (CNP), was commenced in the US in 2008 (APRN Consensus Work Group & National Council of State Boards of Nursing APRN Advisory Committee, 2008). Specialist nurse practice and regulation in Canada is similar to that in the US, whereby a clinical nurse specialists must be Master's prepared at minimum (Canadian Nurses Association, 2009). Certification in various nursing specialities, including oncology, is attained through successful completion of an examination (Canadian Nurses Association, 2009). Ireland moved to introduce minimum education and experience requirements for clinical nurse specialists in 2010 with nurses requiring a minimum of five years post registration experience, two years clinical practice in a specialist area, and a post-graduate diploma to attain accreditation as a CNS (Doody & Bailey, 2011).

Where the US have long required a minimum of Master's level education be attained before accreditation as clinical nurse specialist, minimum education and experience requirements have not been set in all countries for specialist nursing roles. In the United Kingdom the specialist nurse role emerged in the 1970s followed by an unregulated proliferation of specialist nurse roles in the 1990s (Castledine, 2002). Specific accreditation of specialist nurses in the UK exists only for Specialist Community Public Health Nurse (SCPHN) – all other specialist nurses in areas such as cancer nursing have any specialist qualification they may have gained recorded against their registration on the Nursing and Midwifery Council Register (Royal

College of Nursing, 2014). The minimum education requirement to be a specialist nurse in the UK is registration as a nurse, with some specialities requiring an unspecified 'period of experience of sufficient length' to fulfil the role of specialist nurse (Royal College of Nursing, 2014).

A lack of title protection for specialist nurses in the UK has led to inconsistencies in scope of practice, education and training, and career progression (Royal College of Nursing, 2014). A more recent publication by the Royal College of Nursing (2017) providing a framework for cancer nursing now delineates specialist nursing practice from advanced practice, specifying that the term 'specialist' should be used to define the clinical context within which the role is carried out, for example a 'gynaecological oncology specialist nurse'. The level of practice, on the continuum from 'novice to expert', is separate to the context within which the role is carried out. For example a 'senior gynaecological oncology specialist nurse' would indicate that that the nurse was both a specialist in the field of gynaecological oncology but also practicing at 'level six' of the UK 'Skills for health career framework' (Royal College of Nursing, 2017; Skills for Health, 2010). Should the specialist nurse wish to develop their practice to levels seven (advanced) or eight (consultant) the framework indicates that a Master's or Doctorate qualification would be required (Royal College of Nursing, 2017; Skills for Health, 2010).

In New Zealand specialist nurses are not accredited beyond their registration as a nurse with the New Zealand Nursing Council (NZNC). In Australia all nurses must be registered with the Australian Health Practitioner Regulation Agency (AHPRA) however a project was recently established for the credentialing of specialist nurses in the fields of Children and Young People, Mental Health, Emergency and Palliative Care, yet this remains in its early stages (Queensland Health & Australian College of Mental Health Nurses,

2017). The CNS role in New Zealand was first mentioned in policy statements in the 1970s though a formal definition of the role was not released until 1998 (Roberts, Floyd, & Thompson, 2011). It was reported in 2011 that there were inconsistencies in the definition and expectations of CNS roles in NZ (Roberts et al., 2011). A review of CNS job descriptions in New Zealand found that all CNS positions required the incumbent to be a registered nurse with a current practice certificate and have clinical experience in the specialist area though this was not quantified (Roberts et al., 2011). Some CNS positions required that the nurse hold, or be working towards, a postgraduate qualification though the level of qualification was not specified (Roberts et al., 2011).

The CNS roles in the United States, United Kingdom and New Zealand are more likened to the Clinical Nurse Consultant role in New South Wales, Australia (Cashin et al., 2015). It is confusing however that although the clinical nurse consultant (CNC) role has been included in the Enterprise Bargaining Agreements for New South Wales since 1986 (Cashin et al., 2015), an Australian Nursing and Midwifery Federation (ANMF) document on nursing careers, qualifications and experience fails to list this role as part of the nursing career structure in Australia (Australian Nursing and Midwifery Federation, 2009). The role of clinical nurse specialist is included in the document and is specified as an advanced practice role, at the same level as an Associate Nurse Unit Manager. According to the ANMF the CNS role requires a Bachelor of Nursing plus a nursing post-graduate qualification and two to four years post-registration clinical experience (Australian Nursing and Midwifery Federation, 2009). There is significant variance in the nursing award structures of the states and territories of Australia with some including CNC roles and/or CNS roles and others referring to grades only. The nomenclature relating to advanced and specialist nurse roles in Australia is disparate and confusing between states and territories, making comparison of specialist and advanced practice roles difficult.

Specialist nurses in cancer care

Nurses have 'specialised' in cancer nursing since the late 1800s to early 1900s, developing skills and knowledge to assist in early surgical and radiotherapy treatments (Lusk, 2011). As treatment at that time was crude and rarely curative, the provision of supportive care was the mainstay of cancer nursing (Lusk, 2011). Though primitive compared with today, nurses specialising in cancer care in the early 1900s were skilled at caring for colostomies, lymphoedema bandaging, wound care, symptom management and the provision of 'mental hygiene' (Lusk, 2011). The role of the oncology 'field nurse' was described in the literature in the 1950s, involving education and information provision to patients, carers and other nurses, the management of symptoms and side effects, and the organisation of treatment and transportation (Thornton, 1957). It was during the 1950s when the first cancer nursing courses were established in universities in the United States (Lusk, 2005). However, specialisation in oncology nursing has been more formally recognised in the United States since the 1980s (Kwong, Manning, & Koetters, 1982; Siehl, 1982; Welch-McCaffrey, 1986) and is guided by specific oncology specialist nurse competency standards (Oncology Nursing Society, 2008). Similar cancer nursing competency standards also guide the practice of oncology nurses in Australia, New Zealand, Canada, the UK and Europe (Aranda & Yates, 2009; Canadian Association of Nurses in Oncology, 2006; European Oncology Nurses Society, 2013; New Zealand Ministry of Health, 2009; Royal College of Nursing, 2017).

Tumour-specific cancer specialist nursing has been led by specialist breast cancer nurses in Australia. A model of care for specialist nurses caring for women with breast cancer was developed and implemented in Australia nearly two decades ago (National Breast Cancer Centre, 2000). It was recognised however

that there was variation in the implementation of the specialist breast nurse role across Australia, along with variation in educational preparation for the role, delivery of care and skill level. In response, The National Breast Cancer Centre (2005) developed and implemented national competency standards and minimum educations requirements for specialist breast cancer nurses. This document stipulates that specialist breast nurses (SBNs) must hold, at minimum, a post-graduate diploma in breast cancer nursing or cancer nursing in order to develop the advanced level of competence required to fulfil the role (The National Breast Cancer Centre, 2005). Around the same time that the competency standards and minimum education requirements were introduced for breast cancer nurses in Australia, a foundation aimed at funding specialist breast cancer nurses was established (McGrath Foundation, 2017). This organisation now funds, on an ongoing basis, 117 specialist breast cancer nurses at cost of nearly $12M (AUD) per year across Australia where service gaps have been identified (McGrath Foundation, 2017). A qualitative study explored the views of both breast care nurses and women with breast cancer who received care from a McGrath Foundation breast care nurse (Paynter, Foderc, Scuteri, Kerin-Ayres, & Tink, 2013). The study found that participants believed the SBNs improved patient safety, reduced hospital re-admission and emergency department visits, returned time to surgeons, oncologists and allied health staff, and enhanced patients' quality of life (Paynter et al, 2013).

Not all tumour streams however have had the same level of philanthropic support, and consequent development and progression, in Australia. Competency standards have also been developed for specialist nurses caring for men with prostate cancer in Australia, however no minimum education requirement has been set for this role (Sykes, 2013). The Prostate Cancer Foundation of Australia has attracted philanthropic support for the institution of prostate specialist cancer nurses in each state and territory of Australia though not to the same extent as the McGrath Foundation (Sykes, Ferri, Kiernan, Koschade, &

Wood, 2014). Other tumour streams have not benefited from such fiscal support, and the establishment and funding of specialist nursing roles in other cancers is at the discretion of individual public and private health care organisations. Although the inclusion of a specialist nurse as a core member of the multidisciplinary team is recommended for all cancer streams (Cancer Australia, 2014a), the level of equity and access to specialist cancer nursing care in Australia is not known.

Specialist nurses in gynaecological cancer care

Specialist nurses are considered important members of the gynaecological cancer multidisciplinary team in Australia and New Zealand (Cancer Australia & Royal Australian College of Obstetricians and Gynaecologists, 2011; National Gynaecological Cancer Tumour Standards Working Group, 2013) and other countries providing comprehensive treatment of gynaecological cancers (Fung-Kee-Fung et al., 2015; NHS Commissioning Board, 2013). Studies including gynaecological oncology specialist nurses were first published in the late 1990s and early 2000s (Carlsson & Strang, 1998; Jefferies, 2002; Lammers, Schaefer, Ladd, & Echenberg, 2000; Maughan & Clarke, 2001). The efficacy of gynaecological oncology specialist nurses was considered in a quantitative systematic review by Cook, McIntyre, and Recoche (2015). The review considered the effectiveness of specialist nurse interventions on quality of life, satisfaction with care and psychological outcomes in women with gynaecological cancers. The findings of the review indicated that specialist nurse interventions involving comprehensive or individualised care, across all care domains were more effective with regard to quality of life, patient satisfaction with care, feelings of uncertainty and sense of coherence than interventions targeting one domain of care (Cook et al., 2015). It was also found that specialist nurse interventions conducted between diagnosis and the end of treatment were most effective for women with gynaecological cancers. The variability in methodological quality of the studies included in the review limits generalisability of the findings (Cook et al., 2015).

Limited guidelines exist for the practice of specialist nurses caring for women with gynaecological cancer in Australia and New Zealand. Cancer Australia and Royal Australian College of Obstetricians and Gynaecologists (2011, p. 47) provided a brief suggestion for the competency level of a specialist gynaecological oncology nurse, indicating that they required "advanced capabilities for working with women with gynaecological cancer". This document defers to the National Education Framework for Cancer Nursing (EdCan) for the development of competence in specific aspects of gynaecological cancer care (Aranda & Yates, 2009). The framework, also adapted and adopted in New Zealand (New Zealand Ministry of Health, 2009), provides general competency standards for all specialist cancer nurses. There are however no competency standards or guidelines specific to the gynaecological oncology specialist nurse role. The National Gynaecological Cancers Service Delivery and Resource Framework (Cancer Australia & Royal Australian College of Obstetricians and Gynaecologists, 2011) specifies that specialist nurses may be involved in: the assessment and management of women's needs including referral to appropriate services; the provision of information, support and specialist nursing skills; the coordination of care within and across services and sectors; the professional development and mentoring of general nursing staff and strategic service planning; involvement in research and networking. This is further elaborated in guidelines by the National Gynaecological Cancer Tumour Standards Working Group (2013) which specify that the specialist gynaecological oncology nurse should be involved in the management of treatment side effects, including psychosexual issues, and should contact the patient within seven days of their receipt of a cancer diagnosis to commence coordination of their care.

Cancer Australia and Royal Australian College of Obstetricians and Gynaecologists (2011) concede that there are limited opportunities for professional development for specialist gynaecological cancer nurses.

Whilst there are no national education standards for specialist cancer nurses in Australia, Aranda and Yates (2009) stipulate that the development of the EdCan competencies would require post-graduate education. In New Zealand it is specified that an advanced practice nurse would require a post-graduate diploma or Master's degree to competently complete their role (New Zealand Ministry of Health, 2014). A recommendation for specialist gynaecological oncology nurse education in Australia was made by Maidens et al. (2004) and a tertiary-based, week-long education program was developed and evaluated (Philp, Barnett, D'Abrew, & White, 2017). It was found that nurses' confidence in caring for women with gynaecological cancer improved after completion of the program (Philp et al., 2017). In Australia and New Zealand, post-graduate qualifications in gynaecological cancer care do not exist, with post-graduate courses in cancer care or women's health offering the next best alternative.

The number of gynaecological oncology specialist nurses currently working in Australia and New Zealand is not known, though of the 15 specialist gynaecological cancer centres identified in Australia in 2011, 13 included a specialist nurse in their team (Cancer Australia & Royal Australian College of Obstetricians and Gynaecologists, 2011). General nursing workforce statistics in Australia do not allow for the identification of nurses working in the field of gynaecological cancer or any other specific cancer type (Cancer Australia & Royal Australian College of Obstetricians and Gynaecologists, 2011).

Over the past 20 years, the gynaecological oncology specialist nurse role has developed with limited formal direction or control in Australia and New Zealand. No specific competency standards or guidelines for practice have been formulated to direct the specialist nurse role, nor have minimum education or experience requirements been specified for the role. Specialist gynaecological cancer nurses practice

under different job titles within and between jurisdictions as there is limited consensus on the qualifications and minimum levels of experience required to fulfil specialist nurse roles (Aranda & Yates, 2009; National CNS Taskforce, 2010; New Zealand Ministry of Health, 2014; Royal College of Nursing, 2014; Sykes et al., 2014; The National Breast Cancer Centre, 2005).

Theoretical Forestructure

The initial stages of an Interpretive Description (ID) study involve the construction of a 'scaffold' for the study - the initial position from which the study is designed and planned. Thorne (2008) identifies the key elements to a study scaffold as the literature review and the 'theoretical forestructure'. The 'theoretical forestructure' requires the researcher to 'locate' themselves within the field. Thorne (2008) postulates that the theoretical forestructure in an ID study allows for explicit recognition of the researcher as the instrument. This section of Chapter 1 provides the theoretical forestructure of the study by locating the researcher's theoretical allegiances upon entry to the study, locating the researcher within the discipline of gynaecological oncology, and documenting their personal relationship to the study. The theoretical forestructure was written as part of the research proposal and was completed before data collection commenced.

Developing interest in the topic

I first became interested in the role of specialist nurses in gynaecological oncology while working as a Nurse Unit Manager of a gynaecology/gynaecology-oncology ward at private hospital in Melbourne around 8 years ago. At the time there was an experienced nurse fulfilling a part time role as a Clinical Nurse Specialist in gynaecology/gynaecology-oncology on the ward. This nurse was also the hospital

diabetes educator. The diabetes education role was funded as a hospital specialist service however the gynaecology role was funded within the ward budget. That is, the role had to be accommodated within the ward labour hours and nurse-patient ratio budget. This was in comparison to the full-time, hospital specialist service-funded Breast Care Nurse located on the same floor. The breast care nurse also had full leave cover and there were two nurses completing their Master's degrees in preparation to succeed the incumbent. If the gynaecological oncology specialist nurse was on leave, the ward was unable to provide a specialist nurse service during that time. Likewise, if the ward was short staffed the specialist nurse would have to take a patient load given that they were counted as ward staff. Whilst the gynaecological oncology specialist nurse often worked overtime and was challenged by her competing priorities of diabetes education and 'leave reliever', the ward was able to provide a specialist nursing service that was valued highly by the consultants, nursing team and patients.

The hospital had recently been purchased by a large private healthcare provider and there was a new focus on fiscal management. As one of the greatest expenses of running a hospital, nursing costs became scrutinised and the specialist nurse role on the ward was considered by the executive management of the hospital as surplus to the conditions of the Enterprise Bargaining Agreement. Knowing that it would be extremely difficult to maintain the existing level of support for patients and the consultants without the specialist nurse, I searched for evidence to support the role of specialist nurses in gynaecological oncology. I found limited evidence for the role but a significant body of literature supporting the breast care nurse role. Eager to preserve the role and the quality of service provided by the ward, I sought the support of the gynaecological oncologists. They knew that the specialist nurse was a great support to them and their patients throughout what is often a complicated disease and treatment process. The gynaecological

oncologists were successful in securing funding for a part-time specialist nursing service outside of the ward budget.

Whilst the role within the hospital was 'saved', it was concerning that nursing as a profession was not able to provide the evidence to support the role and the role would only exist so long as there was medical support for it. There was also growing support through the Jane McGrath Foundation, paralleled by government support, for the specialist breast nurse role without similar support for other tumour types. The disparity in care available to patients diagnosed with different tumour types was concerning to me. Not only did I understand the situation for women with gynaecological cancer, I also had my father's experience with a rare lymphoma to form my values and beliefs about the benefits of specialist nursing care. I developed a belief that specialist nursing care should be available to all patients with cancer. The opportunity to research the specialist nurse role came through a chance meeting with a university lecturer by whom I had formerly been taught. The lecturer was interested to know what my career plans were and encouraged me to consider a research pathway starting with an Honour's degree. Upon exploring my professional interests and possible topics, my interest in the specialist cancer nurse role was identified as an area requiring research.

Getting to know the literature and the specialist nurses

For my honours degree I completed a systematic review evaluating the effects of specialist nurse interventions on quality of life, satisfaction with care and psychological outcomes of women with gynaecological cancer. This systematic review confirmed that there was very limited evidence available to support the specialist nurse role in gynaecological oncology. During 2013, as I completed my honours

degree, I continued to work as a registered nurse on the gynaecological / gynaecological oncology ward that I was once nurse unit manager of on a permanent part-time and later casual basis. I also became a member of the Cancer Nurses Society of Australia (CNSA) and the gynaecological oncology specialist interest group within that organisation. I attended their annual general meeting held during the 2014 CNSA winter congress in Melbourne and for the first time met some of the specialist nurses working in gynaecological oncology outside of Melbourne. At the meeting I spoke for the first time about my research interests.

In October 2014 I applied to commence my PhD and also applied for a scholarship at this time. My PhD application included a research proposal to investigate the role of specialist nurses in gynaecological oncology in Australia. In November 2014 I presented a poster of the Honours systematic review at the International Gynecological Cancer Society (IGCS) biennial meeting where I met several more nurses working at various levels in gynaecological oncology in both Australia and New Zealand. While standing at my poster during breaks I had several discussions with nurses working in the field about issues such as a lack of education pathways for gynaecological-oncology nurses, coordination of care for women with gynaecological cancer living in large states such as Western Australia, and the development and implementation of psychosocial screening tools in Australia and New Zealand. It became apparent to me through these discussions that different states, sectors and countries were practising the role in different ways and specialist nurses were responding to the needs of the patients within their service rather than having a national, standardised approach to the role. I started seeking the opinion of nurses working in the field about what they felt were the research priorities for their field, which varied, but highlighted that there were many unmet research needs.

Topic development

In December 2014 I was awarded an Australian Postgraduate Award Scholarship along with a Faculty of Medicine Nursing and Health Sciences Postgraduate Excellence Award and commenced my PhD in February 2015. I was very eager to ensure that my PhD targeted the areas of most need in relation to the role of specialist nurses in gynaecological oncology. I spent the first few months of my PhD conducting a systematic review that considered women with gynaecological cancer's experience of specialist nursing care. It became apparent that whilst studies had been conducted to determine the patient's perspective of specialist nursing care, there had been no studies which considered other key stakeholder's perspectives of the role in gynaecological oncology. A study conducted in 2000 in Australia aimed at developing a model of specialist nursing care for women with breast cancer became of great interest to me. The multi-centre study involved the implementation and evaluation of a specialist breast nurse model of care for women with breast cancer. Evaluation of the model of care was through interviews with the patients themselves, the specialist nurses and other members of the treatment team.

Seeking a mandate

The problem now posed was that the specialist nurse role already existed in Australia and the opportunity to evaluate it under 'experimental' conditions had long passed. Yet there was significant opportunity for the role to be further developed and standardised in the way that the specialist breast nurse role had been. I contacted the Chair of the Gynaecological Oncology Special Interest Group (SIG) of CNSA to discuss the different pathways my PhD could take and requested the opportunity to discuss this with members of the group at the upcoming AGM to be held during the CNSA Winter Congress in June 2015. Although I had worked for nearly 10 years in the field of gynaecological oncology and had held a management role,

I still had the feeling of being an 'imposter' with regard to the specialist nurse role having never undertaken this role myself. I was concerned that my research may have been unsolicited or unwanted by the specialist nurses and felt the need to consult with them in the refinement of the topic. Essentially, I was seeking their endorsement and support of the project to ensure that it was going to be of benefit to this group of nurses and in turn the women that they care for. I felt a strong sense of responsibility to ensure that my scholarship money was spent on a worthwhile piece of research.

I made a short presentation to a group of 10 members of the SIG at the CNSA Winter Congress regarding my research of the literature to date and some of the ideas I had for the direction of the project. All present agreed that the role needed greater definition to allow promotion of the service both internally and externally, develop a career pathway for the role, and allow for succession planning. The group also raised concerns about a lack of education opportunities relating directly to gynaecological oncology. Like myself, the group were concerned by the disparity between themselves and the specialist breast nurses and were supportive of this research.

Inclusion of New Zealand in the study

At the 2015 Winter Congress in Perth I also met a colorectal nurse practitioner from New Zealand who was interested in my PhD topic and asked for my contact details to pass on to her colleague in NZ who was a specialist nurse in gynaecological oncology. Shortly after the conference I received an email from the gynaecological oncology specialist nurse expressing interest in the study. We exchanged several emails but it was left at the point that there were no plans to include New Zealand in the study. This however changed when I was contacted by another gynaecological oncology specialist nurse from NZ in

March 2016 who wanted to know more about the study and expressed interest in participating. This nurse was the chair of a Clinical Nurse Specialist group in New Zealand and had completed her Master's on the topic of better defining the clinical nurse specialist role in New Zealand. As a major part of the study recruitment strategy was an invitation emailed to members of the Australia and New Zealand Gynaecological Oncology Group (ANZGOG), I was already conflicted about the exclusion of New Zealand members. As their health system was sufficiently similar to Australia's, and my superficial understanding was that the clinical nurse specialist role was also practiced in a similar manner, it seemed reasonable to consider the inclusion of New Zealand participants in the study. I recalled being asked by a colleague during my confirmation presentation if New Zealand were to be included in the study and replied that I did not feel that there was the mandate to extend the study to New Zealand at the time. It now seemed that I had gained sufficient interest from New Zealand, initiated by them to warrant their inclusion. It too solved the dilemma around excluding New Zealand based ANZGOG members from participating based only on the grounds that they did not work in Australia. Hence, an urgent amendment was sought to the ethics approval that had been granted for the study to include New Zealand participants.

Participant and interviewer relationship

Some of the interview and focus group participants were known to me prior to the interviews being conducted through professional practice or membership of the CNSA Gynaecological Oncology Specialist Interest Group. The survey was purposefully made online and anonymous with no means of tracking respondents. This allowed participants to respond without identification given that the gynaecological oncology workforce within Australia and New Zealand is relatively small and well known to each other. The aims and background of the research project were also presented at the annual conferences of ANZGOG and CNSA in 2016 to raise awareness of the study and drive recruitment. Hence, participants

who attended these presentations would have gained some understanding of my background and motivations for the study.

Purpose, research questions and significance of the study

The overall purpose of this study is to describe and define the specialist nurse role in gynaecological oncology in Australia and New Zealand. Specifically, this study aims to:

1. Describe how specialist nurses contribute to the provision of gynaecological cancer care in Australia and New Zealand.
2. Determine how specialist nurses and other members of the gynaecological oncology treatment team experience and perceive the specialist nurse role.
3. Define the specialist nurse role in the gynaecological oncology setting and make recommendations for future practice and education.

The three broad aims of this research project were translated into five specific research questions.

1. What is the scope of practice of specialist nurses within gynaecological cancer services?
2. What are the similarities and differences in the way the gynaecological oncology specialist nurse role is practiced throughout Australia and New Zealand?
3. How do members of the gynaecological oncology treatment team experience and perceive the specialist nurse role?
4. How do gynaecological oncology specialist nurses experience and perceive their role?
5. What are the ambitions of specialist nurses for the gynaecological oncology specialist nurse role in the future?

This study replicates aspects of a large project completed 18 years ago by the National Breast Cancer Centre (2000) which engaged key stakeholders of the specialist breast care nurse role in Australia in the development and implementation of a model of care. The gynaecological cancer specialist nurse role has previously been investigated to determine the effectiveness of specialist nursing care on outcomes for women with gynaecological cancer (Cook et al., 2015), however the specialist nurse role extends beyond that of direct patient care, with the specialist nurse playing a role within the multidisciplinary team, and within and between their organisation and other health services. Capturing the perspective of all key stakeholders is essential in defining the role of the specialist nurse in gynaecological oncology and this study is the first in Australia and New Zealand to consider the gynaecological oncology specialist nurse role from the perspective of the specialist nurses themselves and other key members of the gynaecological oncology multidisciplinary team. Until the specialist nurse role in gynaecological oncology is clearly defined, progression of the role through the development of education and career pathways, practice guidelines and succession planning remain impeded.

Summary

The incidence, survival and mortality rates of the gynaecological cancers vary greatly between developed and developing nations. In developed nations, where comprehensive treatment and care is available to women with gynaecological cancers, women may have access to specialist nursing care. However, the qualifications, level of experience, scope of practice and governance of gynaecological cancer specialist nurses varies greatly between countries. This compares to the structured development of the specialist breast nurse role in Australia over the past 20 years. The background and motivations of the researcher upon entering this Interpretive Description study were provided in this chapter, forming the theoretical

forestructure of the project and part of the scaffold upon which the study was designed. This study has sought the perspectives of specialist nurses and multidisciplinary team members on the gynaecological oncology specialist nurse role, with the overall aim of describing and defining the role.

Structure of thesis

Over eight chapters, this thesis presents a study aimed at describing and defining the specialist nurse role in the provision of gynaecological cancer care in Australia and New Zealand. The first chapter of the thesis has presented the background to the study including the incidence and burden of gynaecological cancers, and the history and evolution of specialist nursing roles. The theoretical forestructure of this Interpretive Description study was also provided in this chapter, locating the author within the field of gynaecological cancer nursing and the theoretical world surrounding it. The purpose and significance of the study were also presented, and the research questions postulated.

In addition to the theoretical forestructure offered in Chapter 1, both chapters two and three provide reviews of the related literature to complete the 'scaffold' of this Interpretive Description study. Chapter 2 consists of a published qualitative systematic review which investigated the experiences of women with gynaecological cancers cared for by specialist nurses. Chapter 3 is comprised of an integrative review which considered the needs of women with gynaecological cancers across their disease trajectory. A narrative summary of the results of the two reviews is also afforded in Chapter 3. Chapter 4 of this thesis describes the methodology and methods of the study. The use of Interpretive Description as the methodological basis of this study is explained along with a detailed account of the sampling, recruitment, data collection and analysis methods.

Chapter 5 and Chapter 6 present the results of the study. Chapter 5 offers the findings from an online survey completed by both specialist nurses who care for women with gynaecological cancers and other members of the gynaecological oncology workforce from Australia and New Zealand. The results of a thematic analysis of the interview and focus group data collected from gynaecological oncology specialist nurses are provided in Chapter 6.

An interpretation and discussion of the results is given in Chapter 7. The chapter explores the main findings of the study in the context of cancer care provision in Australia and New Zealand and nursing specialisation. Consideration of the future of the role is made. Conclusions to the study are drawn in Chapter 8 and recommendations for practice, policy, education and future research are provided.

Chapter 2 – Systematic review

Introduction

This chapter includes a published paper of a systematic review of the experiences of women with gynaecological cancers cared for by a specialist nurse. Women with gynaecological cancers were not included in this study because their view on the specialist nurse role and their needs, had already been investigated in other studies. The systematic review is one of two literature reviews undertaken as part of the study. The systematic review was completed in accordance with the JBI Reviewer's Manual (Aromataris & Munn, 2017) and the paper was published in the Johanna Briggs Institute Database of Systematic Reviews and Implementation Reports in 2017 (Cook, McIntyre, Recoche, & Lee, 2017).

Systematic review

SYSTEMATIC REVIEW

Experiences of gynecological cancer patients receiving care from specialist nurses: a qualitative systematic review

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EXECUTIVE SUMMARY

Background

The care needs of women with gynecological cancer are complex and change over the course of their cancer journey. Specialist nurses are well positioned to play a role in meeting the needs of women with gynecological cancer although their role and scope of practice have not been well defined. As patients are a key stakeholder, understanding their experience of care is an important step in better defining the role and scope of practice of specialist nurses in gynecological oncology in Australia and New Zealand.

Objectives

This review sought to consider gynecological cancer patients' experiences of specialist nursing care. Exploring the patient's experience of care by a specialist nurse is one step in the process of better defining the role and scope of practice of specialist gynecological-oncology nurses in Australia and New Zealand.

Inclusion criteria

Types of participants

This review included studies with a focus on women with gynecological cancer who had been cared for by a specialist nurse. Studies of women with gynecological cancer at any point on the continuum of care from pre-diagnosis to survivorship or end of life, including those with a recurrence of the disease, were included, with no limit to the duration of care received for inclusion in the review.

Phenomena of interest

Studies that explored how women with gynecological cancer experience the care and interventions of specialist nurses were included.

Types of studies

Qualitative studies including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research were considered for review. This review also considered the qualitative components of mixed method studies.

Context

Research conducted in any country was considered for inclusion in this review providing that the study was reported in English. Studies conducted in any setting including, but not limited to, acute hospitals, outpatient/ambulatory clinics, chemotherapy or radiotherapy units, support groups, palliative care units or the patient's home were included.

Search strategy

A three-step search strategy was utilized in this review. An initial limited search of MEDLINE and CINAHL was undertaken followed by a comprehensive search using all identified keywords and index terms across all included databases. The reference lists of all identified reports and articles were hand searched for additional studies.

Methodological quality

Each paper was independently assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standardized critical appraisal instrument from the Joanna Briggs Institute the Qualitative Assessment and Review Instrument. When disagreement arose between the reviewers, the given paper was independently appraised by a third reviewer.

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There is no conflict of interest in this project.

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Data extraction
Data were extracted from papers included in the review using the standardized data extraction tool from Joanna Briggs Institute the Qualitative Assessment and Review Instrument. Data extraction was completed independently by two reviewers.

Data synthesis
Extracted findings from seven included papers were grouped according to similarity in meaning from which 11 categories were developed. These categories were then subjected to a meta-synthesis that produced a set of three synthesized findings.

Results
Key findings were extracted from six included papers and classified as unequivocal (U) or credible (C). A total of 30 findings were extracted and aggregated into 11 categories based on similarity in meaning. From the 11 categories, three synthesized findings were developed: i) Tailored care: specialist nurses play a role in understanding and meeting the individual needs of women with gynecological cancer; ii) Accessible care: specialist nurses guide women with gynecological cancer along the continuum of care and are an easily accessed source of knowledge and support; iii) Dependable expertise: women with gynecological cancer express trust and reassurance in the experience and expertise of the specialist nurse.

Conclusions
This systematic review synthesized the findings of seven studies that captured the experiences of women with gynecological cancer who received care from a specialist nurse. The specialist nurse offers tailored, accessible and expert care to women with gynecological cancer. From the synthesis it is recommended that women with gynecological cancer have access to the services of a specialist nurse at key points on the continuum of care, that specialist nurses provide information to patients on their disease and treatment in the form preferred by the patient and ensure that this information has been understood, and that specialist nurses are afforded time to spend with patients to enable greater exploration and identification of patient needs and the provision of personalized care. Further study that considers other key stakeholders in the specialist nurse role in gynecological oncology is recommended in order to gain a full understanding of specialist nurses' contribution to the care of women with gynecological cancer. Additionally, it is recommended that further studies be conducted to seek the perspectives of women with gynecological cancer from culturally and linguistically diverse backgrounds and Indigenous populations on specialist nursing care as they appear to be under-represented in current research.

Keywords Advanced practice nursing; gynecological cancer; oncology nursing; specialist nursing; women's experience

JBI Database System Rev Implement Rep 2017; 15(8):2087–2112.

ConQual summary of findings

Systematic review title: Experiences of gynecological cancer patients receiving care from specialist nurses
Population: Women with gynecological cancer cared for by a specialist nurse
Phenomena of interest: How women with gynecological cancer experience the care of a specialist nurse.
Context: Studies conducted in any country or clinical setting.

Synthesized finding	Type of research	Dependability	Credibility	ConQual score	Comments
Tailored care: specialist nurses play a role in understanding and meeting the individual needs of women with gynecological cancer	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Moderate	*Downgraded 1 level due to dependability of primary studies **Downgraded 1 level due to the inclusion of both unequivocal and credible findings.
Accessible care: specialist nurses guide women with gynecological cancer along the continuum of care and are an easily accessed source of knowledge and support	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Moderate	*Downgraded 1 level due to dependability of primary studies **Downgraded 1 level due to the inclusion of both unequivocal and credible findings.
Dependable expertise: women with gynecological cancer express trust and reassurance in the experience and expertise of the specialist nurse	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Moderate	*Downgraded 1 level due to dependability of primary studies **Downgraded 1 level due to the inclusion of both unequivocal and credible findings.

Background

Gynaecological cancer is a collective term referring to cancers of the female reproductive system including cancers of the ovary, cervix, uterus, vulva, vagina and fallopian tubes. Gynecological cancers account for approximately nine per cent of all cancers affecting women in Australia,[1] 10%in New Zealand[2] and around 17% worldwide owing to the significant burden of cervical cancer in developing countries.[3] Despite advances in screening and treatment of gynecological cancers, the incidence of ovarian, uterine and cervical cancers is predicted to rise over the next five years.[1] However, the effect that human papillomavirus (HPV) vaccination will have on new cervical cancer diagnoses, in countries where it is available, is unknown.[1] With no definitive screening tests available to date, women continue to be diagnosed with ovarian cancer in its advanced stages. Consequently, the five-year survival rate for women with ovarian cancer is 43% in Australia as compared to 68% for women with other types of cancer.[4] Five-year survival rates for women with ovarian cancer in New Zealand are lower, at 39%.[5] This poses a significant burden on individuals, families and health care systems.

Women diagnosed with gynecological cancer have care needs, from the pre-diagnosis through to survivorship or end of life phases of the disease. The diagnostic period is one of great distress and where the informational needs of patients and relatives are particularly high.[6-9] Treatment phases are characterized by heightened physical and psychosocial needs related to the side effects of treatment and life adjustment to a cancer diagnosis.[10-12] Whilst treatment pathways differ for each of the gynecological cancers, a woman will typically have surgery followed by chemotherapy and/or radiotherapy. This initial treatment phase is usually complete within six months of diagnosis.

Largely, the care needs of women with gynecological cancer are similar to those of all cancer sufferers[13] although no studies have compared these experiences. However, numerous studies have been conducted over the past few decades exploring the psychosexual needs of women with gynecological cancer, with more recent studies[14-23] finding that these needs are significant and are often unmet. Improvements in diagnostics and treatment of gynecological cancers have seen recent research focused on the increasing needs of women in the survivorship phase. Several studies and reviews have concurred that the need to deal with the fear of cancer recurrence is a common and often an unmet need of women in the post-treatment period,[24-28] along with concerns about those closest to them,[26,29] uncertainty about the future and anxiety,[27,29] and fatigue.[25,26,29,30] Studies have also shown that gynecological cancer patients express a desire for a patient-involved, collaborative approach to post-treatment care.[24,27,29] Thus, the care needs of women with gynecological cancer are complex and change over the course of their cancer journey. Specialist nurses play a role in meeting the needs of women with gynecological cancer though their role and scope of practice have not been well defined to date. This review focused on qualitative studies that highlighted the women's perspective of their needs and the care provided by specialist gynecological cancer nurses in response to those needs.

Site-specific specialist cancer nursing roles began emerging in the 1980 s[31] though studies including gynecological oncology specialist nurses were first published in the late 1990 s and early 2000 s.[32-35] Specialist gynecological cancer nurses practice under different job titles between different countries and there is limited consensus on the qualifications and minimum levels of experience required to fulfil these roles. Likewise, the scope of practice of these roles varies, making it difficult to provide a clear definition of the specialist nurse role in gynecological oncology. Studies conducted in New Zealand,[36] Canada,[37] the United Kingdom, Northern Ireland and Wales[38-40] have all identified the need for specialist nurse roles across various specialties to be more clearly defined. In order to develop the inclusion criteria of this review, some scope of the specialist nurse role in gynecological oncology had to be provided. To achieve this, consideration was given to literature relating to specialist cancer nurse roles in general and existing competency standards. The New Zealand Ministry of Health specifies that an advanced practice specialist nurse should be post-graduate diploma or masters qualified.[41] This is supported in Australia for specialist breast cancer nurses only who must hold a minimum of a graduate diploma in the specialty of cancer nursing[42] and in the US where clinical nurse specialists require a minimum of masters level education for endorsement.[43] Conversely, the Australian prostate cancer

specialist nurses competency standards do not stipulate minimum education or experiencerequirements to fulfill the role,[44] and specialist nurses in the UK are likewise not required to have a qualification beyond that required to become a registered nurse but may require an unspecified period of experience for employment in some roles.[45] Like the UK, neither Australia nor the US stipulate the years of experience required to fulfill the specialist cancer nurse role.[43,45,46] As there is no consensus on the minimum education and experience requirements of a specialist cancer nurse, the proposed review included nurses who were considered to fulfill the functions of the specialist nurse role. Implicitly the specialist nurse may be differentiated from an experienced nurse working in the field of gynecological oncology in that they are specifically employed in a role that includes functions such as coordinator of care, collaborator within the multidisciplinary team, clinical expert, staff and patient educator, researcher and strategic planner.[41-48] Such a nurse may be employed under various job titles, such as clinical nurse specialist, clinical nurse consultant, cancer care coordinator, specialist cancer nurse, liaison nurse, fast track nurse, nurse navigator or advanced practice nurse, depending on the country and setting in which they are employed. This systematic review aims to aggregate evidence pertaining to the patient's experience of specialist nursing in gynecological oncology. As key stakeholders, determining the patient's experience of care is an important step in a current research project aimed at better defining the role and scope of practice of specialist nurses in gynecological oncology in Australia and New Zealand. The background to this systematic review deviates slightly from the published protocol[49] in that reference to the New Zealand context is made to reflect the inclusion of New Zealand in the research project to which this systematic review relates.

In 2014, a quantitative systematic review was conducted to determine the efficacy of specialist nurses in gynecological oncology settings.[50] The review by Cook *et al.* evaluated the effects of interventions by specialist nurses on quality of life, satisfaction with care and psychological outcomes of women with gynecological cancer.[50] The psychological outcomes considered were uncertainty, depression, anxiety, confusion, anger, self-esteem, body image, distress and sense of coherence.[50] The review by Cook *et al.*[50] also categorized interventions according to four main domains of care: informational and educational; social, emotional and psychological; physical and practical; and psychosexual; and considered the effectiveness of each. Likewise, the effects of specialist nurse interventions when delivered at different points on the continuum of care, via different modes of delivery or at varying intensity, frequency or duration, were also considered in the review by Cook *et al.*[50] The review included six randomized controlled trials and three non-randomized quantitative studies which varied greatly in their study design and methodological quality, thus preventing a meta-analysis of the findings. The findings of the review were that interventions involving comprehensive or individualized care across all care domains positively affected quality of life, patient satisfaction, uncertainty and sense of coherence.[50] However, the authors of the review concluded that variability in the methodological quality of the included studies made generalization of the findings difficult.[50] Timing of care was also shown to be important, with interventions conducted between the point of diagnosis and the end of treatment found to be the most effective. The 2014 review by Cook *et al.*[50] excluded the qualitative arms of included studies and other relevant qualitative evidence on the basis of resource constraints; however it acknowledged that such evidence must also be evaluated in order to fully comprehend how women with gynecological cancer experienced the care of specialist nurses. A preliminary search of the relevant databases for existing systematic reviews on this topic, including the *JBI Database of Systematic Reviews and Implementation Reports*, the Cochrane Library, CINAHL, PubMed and PROSPERO, revealed that only the abovementioned review has been conducted.[50] The current systematic review was undertaken to synthesize the existing qualitative evidence in order to determine how women with gynecological cancer experienced the care of specialist nurses. This review was anticipated to provide an added dimension to the Cook *et al.*[50] review by exploring women's experiences of specialist nursing care that might not otherwise be captured through quantitative measures such as quality of life and psychological outcomes.

Review question/objectives

This review sought to explore gynecological cancer patients' experiences of specialist nursing

care. Determining patients' experiences of care by a specialist nurse is one step in a current research project aimed at better defining the role and scope of practice of specialist gynecological-oncology nurses in Australia and New Zealand.

Inclusion criteria

Types of participants

This review considered studies that included women with gynecological cancer who had been cared for by a specialist nurse. For the purpose of this review, gynecological cancer is a collective term used to refer to cancers of the ovary, endometrium, uterus, cervix, vagina, fallopian tubes and vulva. Care from a specialist nurse may have taken place at any point on the continuum of care from pre-diagnosis to survivorship or end of life, including those with a recurrence of the disease and there was no limit to the duration of care received for inclusion in this review.

Phenomena of interest

This review considered studies that explored how women with gynecological cancer experienced the care and interventions of specialist nurses. This review did not include studies where care was provided by nurses other than those employed in a specialist nurse role. The specialist nurses' job titles may have included: clinical nurse specialist, cancer nurse consultant, cancer care coordinator, specialist cancer nurse, liaison nurse, nurse navigator or advanced practice nurse, depending on the country and setting in which they are employed. This review excluded studies with nurses who may have been experienced in the care of women with gynecological cancer but had not been employed in a specialist role. Likewise, studies including women cared for by a nurse practitioner were excluded, as the nurse practitioner role is considered a more advanced and specific role than that of the specialist nurse.[46,47]

Context

Studies conducted in any country were included in this review providing that the study was reported in English. This review considered studies conducted in any setting including, but not limited to, acute hospitals, outpatient/ambulatory clinics, chemotherapy or radiotherapy units, support groups, palliative care units or the patient's home.

Types of studies

Qualitative studies including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research were considered for review. This review also considered the qualitative components of mixed method studies.

Search strategy

The search strategy aimed to find both published and unpublished studies. A three-step search strategy was utilized in this review. An initial limited search of MEDLINE and CINAHL was undertaken followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second search using all identified keywords and index terms was undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles were searched for additional studies. Studies published in English were considered for inclusion in this review as the reviewers comprehend English only. As the specialist nurse role in gynecological oncology first emerged approximately 20 years ago the search strategy was limited to studies published between 1995 and 2015. This search was updated to include 2015–2017 prior to publication.

The databases searched were: PubMed, Embase, CINAHL, PsycINFO, AMED and Scopus.

The search for unpublished studies included: ProQuest Dissertations and Theses, Dissertation Abstracts International, Thesis Canada Portal, Networked Digital Library of Theses and Dissertations (NDLTD) and Caresearch.

Keywords related to "gynecological cancer" and "specialist nursing" were used in the searches of each database. Search results relating to "gynecological cancer" were then combined with the Boolean operator "OR" as were those relating to "specialist nursing". The two groups of search results were then combined with the Boolean operator "AND" to provide the final search results for a given database. The initial search was conducted in April 2015 and the search updated in March 2017.

Appropriate MeSH terms and subject headings were also utilized in the search strategy for the databases that possessed such function.

Assessment of methodological quality

Each eligible paper was assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standardized

critical appraisal instrument from the Joanna Briggs Institute the Qualitative Assessment and Review Instrument (JBI-QARI).[51] When disagreement arose between the reviewers, a third reviewer independently appraised the paper.

Data extraction

Data were extracted from papers included in the review using the standardized data extraction tool from JBI-QARI.[51] Data extraction was completed independently by two reviewers. A third reviewer was utilized when discrepancies arose in the data extracted by the initial two reviewers. The extracted data included specific details about the phenomena of interest, populations, study methods and specific objectives.

Data synthesis

Qualitative research findings were identified through the reading and re-reading of each of the included papers and entered into JBI-QARI. All findings were assessed for relevance to the research question and allocated a status of 'included' or 'excluded' within JBI-QARI. Included findings were then grouped according to similarity in meaning from which categories were developed by the chief reviewer and then verified and accepted by all reviewers. Within JBI-QARI, all included findings were assigned to a category. These categories were then subjected to a meta-synthesis that produced a single comprehensive set of synthesized findings. Some of the study's findings could have been allocated to more than one category and likewise some categories traversed more than one synthesized finding. The illustrations were thus used for greater differentiation and allocation of the study findings to the most suitable categories.

Results

Description of studies

A total of 3197 studies were identified through implementation of the search strategy. Review of the title and abstracts of led to the exclusion of 3142 papers leaving 55 papers for full text review. Of these, 44 were excluded as they did not meet the inclusion criteria. Eleven papers[34,35,52-60] were appraised for methodological quality and for confirmation that they met the inclusion criteria by a second reviewer. Appendix I shows the results of the appraisals and denotes the reason for exclusion of four papers.[34,35,55,57] Data were extracted from the remaining seven included papers for synthesis.[52-54,56,58-60] The characteristics of the seven included articles can be found in Appendix II. Figure 1 below is a PRISMA flow chart of the search results and study selection process.[61]

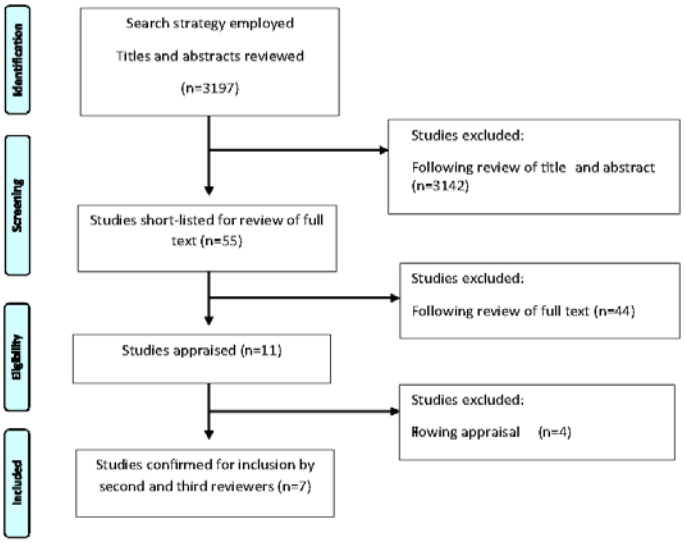

Figure 1: PRISMA flowchart of study selection and inclusion process[61]

Table 1: Methodological quality of included studies

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Thygesen, Pedersen, Kragstrup, Wagner & Mogensen[52]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Lloyd, Briggs, Kane, Jeyarajah & Shepherd[53]	Y	Y	Y	Y	Y	UC	Y	Y	Y	Y
Guest, Manderville & Thompson[54]	UC	UC	Y	UC	UC	Y	N	Y	UC	Y
Cox & Faithfull[56]	Y	Y	Y	Y	Y	UC	Y	Y	Y	Y
Lydon, Beaver, Newbery & Wray[58]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Philp, Carter, Bernett, D'Abrew, Pather & White[59]	UC	Y	Y	Y	Y	N	N	Y	Y	N
Kobleder, Mayer & Senn[60]	UC	Y	Y	Y	Y	N	UC	Y	Y	Y

N, No, feature not present; UC, unclear; Y, Yes, feature present.

Methodological quality of included studies

Six[52,53,56,58-60] of the seven included papers were assessed as being of high methodological quality with Guest *et al.*[54] assessed as low-moderate quality when utilizing the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI)[51]. Table 1 represents the results for each of the 10 criteria each paper was assessed against.

All seven of the included studies[52-54,56,58-60] demonstrated congruence between their stated methodology and their data collection strategies. Representation and analysis of the data and interpretation of the results was aligned with the methodology for six of the included studies [52,53,56,58-60] Guest *et al.*[54] was the only paper to provide a statement locating the researcher culturally, however the influence of the researcher on the research was not acknowledged in the case of Guest *et al.*[54] or Philp *et al.*[59] In these studies, the potential feeling of obligation or gratitude to the researcher (the specialist nurse) on the part of the patient was not explicitly discussed.[54,59] Kobleder *et al.*[60] provided explanation of their independent coding process to mitigate bias in the analysis of transcripts, however they did not discuss the influence of the researcher prior to this. All other included papers[52,53,56,58] adequately addressed any influences that the researcher may have had on the research or vice versa. The participants' voices were adequately represented by each of the included studies and the conclusions drawn were all congruous with the analysis and interpretation of the data.[52-54,56,58-60]

The study conducted by Guest *et al.*[54] was assessed to have not met, or it was unclear as to whether it met, six of the ten assessment criteria. Guest *et al.*[54] inadequately reported on two distinct arms of their study, with different methodologies, within one paper which made the methodology and representation of data and interpretation of results incongruous. This paper[54] also failed to denote the philosophical perspective of the research as did the papers by Philp *et al.*[59] and Kobleder *et al.*[60] The Guest *et al.* paper lacked congruity between the stated research methodology and research question/objectives. The structure of the Guest *et al.*[54] paper also made it difficult to determine cohesion between the representation and analysis of the data and interpretation of the results with the methodology. Guest *et al.*[54] was the only included paper where the ethics-related processes of the research were not made clear. Yet, the voices of the women who participated in this study were well represented and were deemed by the reviewers to be valuable to the review objective.[54] Indeed, exclusion of this paper would have excluded a relevant and rich account of the experiences of women with gynecological cancer of specialist nursing care.[54] Had the women's voices not been presented in this manner, this study would have been excluded from this review on the basis of its otherwise poor methodological quality.[54]

Characteristics of included studies and participants

Four of the seven included studies were conducted in the UK,[53,54,56,58] one study in Denmark,[52] one in

Switzerland[60] and another in Australia.[59] Six of the seven studies determined women's experiences of services provided by a specialist nurse solely or as part of a team.[52,54,56,58-60] In the remaining study, women shared their experiences of specialist nursing care as part of an overall study on their lived experiences of trachelectomy surgery for cervical cancer.[53] The studies were conducted when the participants were at different points on the care continuum including pre-operative,[54,59] at diagnosis,[52] during and after treatment[52,53,59,60] and in follow-up.[56,58]

A total of 76 women participated in the seven included studies.[52-54,56,58-60] The majority of participants had ovarian cancer though three studies included women with all types of gynecological cancer,[52,54,59] one with cervical cancer only[53] and another with vulvar neoplasia only.[60] Demographic and clinical data on the participants were not presented in one study.[54] The age of participants ranged from 29–84 years in the other five studies.[52,53,56,58-60]

The roles of the specialist nurses in each of the studies differed. The included studies conducted in the UK[53,54,56,58] all related to care provided by a "Clinical Nurse Specialist". The Danish study[52] considered the care provided by a "Nurse Navigator" and participants in the Australian study[59] were cared for by a "Fast-Track Nurse", a role filled by an experienced "Clinical Nurse Consultant". In the Swiss study, care was provided by an Advanced Practice Nurse with a master's degree or equivalent and extended clinical practice.[60] A summary of the characteristics of the seven included studies can be found in Appendix II.

Results of meta-synthesis of qualitative research findings

Key findings were extracted from the seven included papers and classified as unequivocal (U) or credible (C). A total of 30 findings were extracted and aggregated into 11 categories based on similarity in meaning. From the 11 categories, three synthesized findings were developed.

Each of the synthesized findings are described below along with an explanation of the categories from which they were derived. The explanations provided for each of the synthesized findings and categories are based on the findings of the included studies only. The findings and supporting illustrations for each category are also provided. All illustrations are referenced to the page, column and paragraph of the article from which they were extracted.

Synthesized finding 1. Tailored care: specialist nurses play a role in understanding and meeting the individual needs of women with gynecological cancer

Although there are many experiences and emotions common to all women diagnosed with gynecological cancer, each woman has their own unique response to their illness influenced greatly by their current and past life experiences. In order to provide optimal care for women with gynecological cancer, clinicians must assess the individual's needs and tailor care to meet these needs. The specialist nurse is a key provider of information and support to the woman with gynecological cancer but must ensure that the information and support provided are timely and sensitive to the woman's current needs. Regular and formal assessment is important in ensuring that changing needs along the disease trajectory are identified and addressed. The experience and knowledge of the specialist nurse also play a role in their ability to anticipate the needs of women with gynecological cancer. The close relationship that often develops between the woman and her specialist nurse also assists the specialist nurse in developing a deeper understanding of a patient's needs. Similarly, the extra time taken by specialist nurses to assess the individual needs of patients also facilitates the provision of tailored care. The patients' perception that the specialist nurse has more time to spend with them makes the patient feel well cared for. Five categories were combined to form this synthesized finding:

- Source of information and support
- Assessment of needs
- A close relationship
- Not constrained by time
- Anticipate needs.

Category 1.1: Source of support and information

A cancer diagnosis can raise many questions for the patient and their family and friends. The provision of information about their condition and its treatment and side effects is important to ensure that the patient feels empowered to make informed decisions about their care. Patients diagnosed with cancer often require significant emotional support to manage the grief and emotional strain that inevitably accompany a cancer diagnosis.

Finding 1: Experience of help and support after trachelectomy surgery. Many women indicated that they found their Clinical Nurse Specialist (CNS) beneficial for information and support (U)

- Illustration 1: "Someone to talk things through." (p.367)[53, column 2, para 3]
- Illustration 2: "Putting them at ease." (p.367)[53, column 2, para 3]
- Illustration 3: "Answers to questions." (p.367)[53, column 2, para 3]
- Illustration 4: "Providing information in an understandable way" (p.367)[53, column 2, para 3]
- Illustration 5: "Judge what was needed at that time." (p.367)[53, column 2, para 3.]

Finding 2: Need for support and information. the time between the end of treatment and the first follow-up visit (usually three months) was when participants reported feeling most "vulnerable". (C)

- Illustration 6: "I know that when I come to clinic I would constantly look out for [oncology nurse], I don't know why because I didn't need to ask anything. I think it was just reassurance that you were there." (p.339)[58, column 2, para 4]

Finding 3: Support and information (C)

- Illustration 7: "Previously, I was thrown in, this time what helped was getting together with the nurse; she had a plan." (p.28)[54, column 2, para 1]

Category 1.2: Assessment of needs

Regular assessment of needs in women with gynecological cancer can identify problems that the patient may not be aware of or unable to articulate and alerts the nurse to issues that may need attention. Specialist nurses may use a formal screening tool to assess patients on a regular basis and follow protocols for referral to additional services where indicated.

Finding 4: Holistic assessment (C)

- Illustration 8: "It was good; there were things when I saw them in black and white on the form, I would not have thought they concerned me." (p.28)[54, column 2, para 4]
- Illustration 9: "It confirmed what my worries were, it was a real help." (p.28)[54, column 2, para 4]

Category 1.3: A close relationship

The relationship a patient develops with a specialist nurse is different from many of the relationships that they have with other health professionals. Whilst purposeful and professional, the relationship between the patient and specialist nurse is ongoing and therefore lends itself to the parties forming a "professional friendship". The relationship is therapeutic, offering the woman an opportunity to discuss their concerns in a less formal way without burdening family or friends. The development of a close relationship may however be dependent on the compatibility of the personalities of the patient and specialist nurse.

Finding 5: A little bit more personal (U)

- Illustration 10: "You see so many different people as well and you don't really, very often see the same person twice, that I think is quite off putting. Even now, I find it off putting. Everybody's nice, they say "I'm so and so" and that immediately goes straight out of my head and I think well probably my name goes out of theirs because they see so many people." (p.2360)[56, column 1, para 1]
- Illustration 11: "It was, it was consistency, it was um... the feeling that I was being looked after, that somebody was looking out for me, because it is scary, you do go to a scary place then and you, you, and... the feeling that it could, you know it could happen again or you know something like that, it takes a while to go away and its knowing somebody that you feel you trust um... and who understands you, I feel that's very important." (p.2360)[56, column 1, para 3]
- Illustration 12: "There's always someone different in the clinic, I mean they just read your notes and talk to you about whatever it is in your notes, whereas I spoke to [nurse 2] on the phone I always spoke to the same person... I mean I've never seen the girls (laughs) so its not like... I saw [Nurse 1], but I just feel that, I think it's a little bit more personal that way, because it's the same person on the phone every time, I say I don't know what she looks like, I've never seen her but I just feel that I know her because she's the same person that I speak to every time." (p.2360)[56, column 1, para 4]

Finding 6: Like talking to a friend (U)

- Illustration 13: "It made me better though because I feel a bit confident and comfortable with her and she was very good and I feel a bit safe you know, you know I feel like she's looking after me." (p.2361)[56, column 1, para 5]

- Illustration 14: "You get to know them...its more sort of friendly you know. Like I was talking to [nurse 2] about her pregnancy, once I got all my lot out of the way...and that is quite nice. That is like talking to a friend really, and it's not clinical." (p.2361)[56, column 1, para 7]
- Illustration 15: "Knowing that someone was going to be phoning me and I had a little query about something and I could pass that over was almost a feeling of relief really, whoever I spoke to never questioned why I asked that..[..]..it was a support that I had not expected." (p.2361)[56, column 2, para 1]

Finding 7: Therapeutic relationship (C)
- Illustration 16: "It was reassuring to know that things I might have worried about, somebody else had taken that away from me." (p.28)[54, column 2, para 2]
- Illustration 17: "They put my mind at ease." (p.28) [54, column 2, para 2]
- Illustration 18: "They understand you better....were given permission to cry and to say what your feelings are – my family; I don't want to reveal all, I don't want to upset them." (p.28)[54, column 2, para 2]

Finding 8: A trusting relationship (U)
- Illustration 19: "She was a human being (laughs). I mean she was such a kindhearted person, talking to her was amazing. She had such a tactfulness. That was really what I needed at that time." (p.460)[60, column 1, para 4]
- Illustration 20: "She [APN] was a very quiet person. She was very nice, but maybe I would have needed a person with another personality to talk about certain things." (p.460)[60, column 1, para 6]
- Illustration 21: "It's better that she is a woman. Nothing against men. But for me personally, maybe other women think differently, I am self-conscious, I couldn't have talked in that way to a man." (p.460)[60, column 2, para 3]

Finding 9: Feeling someone is there for you (U)
- Illustration 22: "She [APN] came, that was before surgery, that was perfect, I was able to cry and I could get it off my chest, and also after surgery it was perfect that I could talk to her, and then I was in the hospital for the follow-up (...) that was the first follow-up appointment, when I didn't know what were the test results and then I could talk to her and that was simply reassuring." (p.461)[60, column 2, para 5]
- Illustration 23:"I didn't have the feeling, that I need psychological support. This was kind of covered by her [APN]. Yes I think so. I mean, that I could talk to her. That was like, that I could talk to her was enough for me and I didn't get depressed or something like that." (p.461)[60, column 2, para 9]

Category 1.4: Not constrained by time

Patients perceive that the specialist nurse has more time to spend with them. Patients are conscious of not wanting to bother medical staff or busy ward nurses with their issues beyond the current task at hand and their specialist nurse fills this need. Some patients want to talk about their issues without concern for a health professional's busy schedule or burdening their family member or friend. The patient's perception that the specialist nurse has more 'time' to spend with them is one aspect upon which they distinguish their care from others in the treatment team.

Finding 10: Time was never an issue (U)
- Illustration 24: "I felt that time was never an issue, that whatever I wanted to talk about was, it was relevant. The time was given and it was discussed and that was good." (p.2362)[56, column 1, para 4]
- Illustration 25: "I was never conscious that I was over running my time which was a good thing and I hadn't thought about that until about the second one in, when I put the phone down and I thought 'oh my gosh I've been on there 10 minutes, I wonder if that was too long' and I think I mentioned that next time to [nurse 3] or whoever phoned, I said 'do you have a time limit here' and she said 'NOT at all' and it was a very definite 'NOT AT ALL' and that made you relax again, because you weren't being rushed." (p.2362)[56, column 1, para 5]

Category 1.5: Anticipate needs

The specialist nurse should anticipate what information and support is relevant for the patient at a given time. The specialist nurse should deliver the information in more than one mode, for example, both written material and verbally according to the ability of the patient to receive such information at that time. A cancer diagnosis can make large amounts of information difficult to absorb and the specialist

nurse is able to recognize the need to reinforce and revisit important issues when the patient is most receptive. The specialist nurse follows up the delivery of a diagnosis by medical staff with further written and verbal information but identifies when the patient is ready to receive this.

Finding 11: Discharge information (C)

- Illustration 26: "... I guess in a sense because you're just, you're worrying or...you're spending too much time thinking about it so maybe just a little, a prompt sheet you know would be helpful" (p.162)[59, column 2, para 4]

Finding 12: Emotional needs (pre-admission): shock of cancer diagnosis (U)

- Illustration 27: "There really needs to be counselling...in order to help someone sign the consent and go ahead and have surgery." (p.161)[59, column 2, para 3]
- Illustration 28: "Afterwards it [emotions] sort of just hits you, you know" (p.161)[59, column 2, para 4]
- Illustration 29: "...there's always the, I suppose the... fear of the unknown but you know that was something that I was prepared I had as much information I think as I could have been given so I was relieved." (p.162)[59, column 1, para 1]
- Illustration 30: "Well I have a great support network...by having all of my questions answered if I had concerns I think emotionally that, that made me feel a lot better. I wasn't stressed, I wasn't concerned...having the support of the hospital and then having people able to ask, answer questions helped and I also had the support of family and friends." (p.162)[59, column 1, para 3]

Finding 13: Practical needs (pre-admission): expectations, contact information & medical information needs (C)

- Illustration 31: "...the most helpful was [the FTN]...but I just remember thinking at the time that she was extremely thorough in terms of what I should expect. She went through...you know just all the steps of what was going to happen." (p.161)[59, column 1 para 5]
- *Finding 14:* Pre-admission: involved process with a lot of information to absorb (C)
- Illustration 32: "The information was great but in myself personally I was in - a bit of a horror. I was just in a bit of shock." (p.161)[59, column 1, para 1]
- Illustration 33: "...ah you're given written information but you're not given that information verbally. I didn't feel, I mean I sort of felt ah that I had that in the, in the paperwork that I got given, but I'd probably in terms of verbal instructions for that, I think that I could have done with more there." (p.161)[59, column 1, para 2]

Table 2 below provides a summary of the findings and categories for synthesized finding 1.

Synthesized finding 2. Accessible care: Specialist nurses guide women with gynecological cancer along the continuum of care and are an easily accessed source of knowledge and support

As the gynecological cancers often require more than one mode of treatment, the specialist nurse plays an important role in navigating the patient through the phases of care. Access and referral to medical specialists, allied health and ancillary care are often coordinated by the specialist nurse making them a central point of contact for the patient. Patients are often unsure who they should contact with a concern and express reluctance to contact their busy medical specialists with minor issues. The specialist nurse is an easily accessed health professional who knows the patient well and can either attend to the issue themselves or provide appropriate advice and referral. Even when the patient has no need to contact the specialist nurse, they are reassured by the fact that they can. When treatment and acute care are complete, the specialist nurse offers an ongoing source of support and information throughout survivorship. Three categories were synthesized for accessible care:

- Always available
- Coordination of care
- Survivorship.

Category 2.1: Always available

Having a health professional available at all times who knows the patient well and makes them feel that it is not a problem to contact the professional, no matter what the issue, is highly valued by patients. The continuity of care that this arrangement enables ensures that patients will seek care in a timely manner. A cancer patient's medical history can be long and complex, and arduous for the patient to recount, and this may form a barrier to them seeking help outside of their scheduled appointments with their medical specialist. The specialist nurse offers

Table 2: Results of meta-synthesis 1

Synthesized finding	Category	Findings
Tailored care: specialist nurses play a role in understanding and meeting the individual needs of women with gynecological cancer.	Source of support and information	• Experience of help and support after trachelectomy surgery. Many women indicated that they found their Clinical Nurse Specialist (CNS) beneficial for information and support (U) • Need for support and information – vulnerable in first 3 months needing more contact, specialist information and support (C) • Support and information (C)
	Assessment of needs	• Holistic assessment (C)
	A close relationship	• A little bit more personal (U) • Like talking to a friend (U) • Therapeutic relationship (C) • A trusting relationship (U) • Feeling someone is there for you (U)
	Not constrained by time	• Time was never an issue (U)
	Anticipate needs	• Discharge Information (C) • Emotional needs (pre-admission): shock of cancer diagnosis (U) • Practical needs (pre-admission): expectations, contact information and medical information needs (C) • Pre-admission: involved process with a lot of information to absorb (C)

instant access to clinical judgment and support and will either manage the issue themselves or refer the patient appropriately. This arrangement is not only reassuring to the patient but may also prevent unnecessary and costly trips to the emergency department or GP. Even if the patient has no need to access the specialist nurse, knowing that they are available any time is reassuring to the patient.

Finding 15: Instant access back to clinical judgment and reassurance (U)

- Illustration 34: "I used to make myself little cards that I carry round with me, one in my handbag, one at home here and one in my filing cabinet at work, so if I ever felt I needed to ring her up I've got... ready access." (p.2361)[56, column 2, para 3]

Finding 16: There's always somebody there (U)

- Illustration 35: "There was one time, about the third or fourth one I had a funny symptom, something I'd never experienced before, and I told the nurse and she said 'oh I think that could be so and so, and if you do this first, but if it's still there, phone me' so again I didn't worry, and then it was just as she said it was and I thought that was really good because if I'd been in the consultancy rooms and that had happened I don't know who I would have phoned, not really. You have this emergency number but it wasn't an emergency so I wouldn't have done that, what do I do? Wait until the next appointment and then you know I might have done it wrong and so again there was somebody there, somebody to hold on to almost. So you feel a lot better." (p.2360)[56, column 2, para 3]

Finding 17: Emotional support and reassurance (C)

- Illustration 36: "... The bit [of preadmission] that was good was that I waited and I spoke to the nurse clinician ...and that was really good. That was the best part because she explained more about what was going to happen and, and that was very valuable." (p.163)[59, column 2, para 5.]
- Illustration 37:"...the fast track service was excellent...being able to contact someone virtually immediately and have whatever concern I had eased rapidly rather than sit and you know worry about it, stew about it. I felt that that actually... I suppose let me... I suppose improve and my health improved, I think a lot quicker by knowing that support was there." (p.163)[59, column 2, para 7]

Finding 18: Support at home (C)

- Illustration 38: "...when I came home...there were several questions that I needed to ask and I

was able to contact [Name] who is the fast track nurse and as I say I was, that alleviated a lot of my concern." (p.163)[59, column 1, para 2]

Finding 19: The nurse-led follow-up clinic and coordination role (C)

- Illustration 39: "Good to have an, have an interim sort of appointment." (p.163)[59, column 2, para 8]
- Illustration 40: "Cause sometimes it seems a long time til you get to see the specialist after." (p.164)[59, column 1, para 1]
- Illustration 41: "...[FTN] was very very good at saying to ring anytime and if you know if I had any questions ...yeah she in particular seemed to be the, link person...you know so it was nice, it was nice to have her there as the, the go between and she was, she has been terrific in, in that respect...to ring anytime with questions and concerns." (p.164)[59, column 1, para 2]

Finding 20: Accessibility (U)

- Illustration 42: "And that was (...) that was simply such an amazing feeling. I think it's not only (.) that you have to ask questions but simply to know, if I have a question, then I can (.) then I can call her [APN]." (p.460)[60, column 2, para 5]
- Illustration 43: "I had no need to call her [APN] but of course it is helpful, if you (...) especially after discharge she [APN] said, if there are any questions then I should call her and she told me when and how. But I didn't have to, but it could have been." (p.460)[60, column 2, para 7]
- Illustration 44: "I knew I could call her [APN] anytime. This was simply reassuring. Something could have happened, the wound could have started bleeding again. Before contacting the physician, I would have called her [APN]." (p.460)[60, column 2, para 9]

Category 2.2: Coordination of care

Navigating their way through treatment can be a daunting prospect for cancer patients, particularly for those with no prior experience as a hospital patient. The specialist nurse plays a role in ensuring that patients move through their treatment schedule in a timely and organized manner without getting lost along the way. Coordination of care may be largely administrative and involve booking appointments and scheduling treatment. Having a close relationship with the patient enables the specialist nurse to perform this task in a way that is least obtrusive to the patient and their life.

Finding 21: Coordination of care (C)

- Illustration 45: "I would have been really lost without her, she got things in motion." (p.28)[54, column 2, para 5]
- Illustration 46: "It was good having an advocate." (p.28)[54, column 2, para 5]

Category 2.3: Survivorship

Survivorship is a time when appointments with medical specialists become less frequent and aimed at detecting recurrence. However the needs of women in survivorship are greater than this and specialist nurses are well placed to assess and meet (directly or through referral) the needs of women at this stage, especially when they have a well established relationship.

Finding 22: Future provision for survivors of ovarian cancer (C)

- Illustration 47: "My feelings are very, very positive about telephone follow-up and I would say to anybody who was thinking about how they would best like to be seen is to go for the telephone follow-up if you can." (p.2362)[56, column 2, para 1]

Table 3 below provides a summary of the findings and categories for synthesized finding 2.

Synthesized finding 3. Dependable expertise: Women with gynecological cancer express trust and reassurance in the experience and expertise of the specialist nurse

The specialist nurse offers women with gynecological cancer a source of expert advice that is reassuring to the patient. Women with gynecological cancer utilize well-experienced and knowledgeable specialist nurses as sources of advice and reassurance. Patients are comfortable in approaching their specialist nurse first with a clinical query and seek their advice as to whether medical opinion should be sought. In this way, specialist nurses provide an easily accessible knowledge bank for patients to draw on. This provides the patient with a sense of safety and security. The provision of routine follow-up blood test results is also an important part of some specialist nurse roles and a vital component of their ability to provide reassurance to the patient.

Table 3: Results of meta-synthesis 2

Synthesized finding	Category	Findings
Accessible care: specialist nurses guide women with gynecological cancer along the continuum of care and are an easily accessed source of knowledge and support	Always available	• Instant access back to clinical judgement and reassurance (U) • There's always somebody there (U) • Emotional support and reassurance (C) • Support at home (C) • The nurse-led follow-up clinic and coordination role • Accessibility (U)
	Coordination of care	• Coordination of care (C)
	Survivorship	• Future provision for survivors of ovarian cancer (C)

Three categories were combined to form this synthesized finding:

- Trust in the specialist nurse
- Need for reassurance
- Clinical expertise.

Category 3.1: Trust in the specialist nurse

The knowledge and experience of the specialist nurse facilitate the patient's trust and confidence in them. The patient feels confident that they can present to the specialist nurse with a problem and they will know what to do. Patients are reassured by the experience on which the specialist nurse is able to draw and in learning that their experience is not unique or unusual.

Finding 23: She will know – trust in the expertise of the nurse (U)

- Illustration 48: "I think I'd probably phone [nurse 2] first and say do you think I should go to my doctor because I feel that she's the expert." (p.2361)[56, column 2, para 4]
- Illustration 49: "She'll know. . ..if you say such and such and such and such she will know that there is a problem." (p.2361)[56, column 2, para 4]

Finding 24: Trust in the NN – those who used NN found her to be kind and calming (U)

- Illustration 50: "The NN was, in fact, quite nice. . . she was able to tell me more. . . and she explained things, so I really trusted her (ok). . . it was before treatment. . . and everything was uncertain (yes), so I got the opportunity to ask some questions (ok), and I actually remember that she said that she had 25 years of experience; she had seen some things, and they would result in such and such. . . and that I should take it easy and so on (yes). . . and I was much relieved (yes), really. . . [the NN] had a professional attitude. . ." (p.7)[52, column 1, para 2]

Finding 25: Feeling safe and secure (C)

- Illustration 51: "My questions often concerned what I am allowed to do and what not, because the information in the hospital is often not so (. . .) not always there (. . .) they [medical staff in hospital] didn't explained it and they didn't give me hints how to relieve the pain and so on." (p.461)[60, column 1, para 3]
- Illustration 52: "Of course, she [APN] can't choose a therapy option for me. But she supported me by discussing the pros and cons, she listened to me, she was sympathetic. She didn't have this firm attitude like the physicians." (p.461)[60, column 2, para 6]
- Illustration 53: "She [APN] had organisational skills, if you as a patient do not have an overview anymore it helps a lot if someone organises appointments and further healthcare services. That's very valuable." (p.461)[60, column 2, para 1]
- Illustration 54: "(. . .) I had more time with her [APN], I had much more time to exchange experiences with her, in contrast to the physician, for me he [physician] was anywhere, I knew he did the surgery, I knew he is a good physician, but there was not more. But with her [APN] I was really able to exchange experiences, also via telephone (. . .)" (p.461)[60, column 2, para 3]

Category 3.2 Need for reassurance

Follow-up appointments for women with gynecological cancer are generally focused on detection of

recurrence through blood tests and examination. Women report feeling reassured by this regular, scheduled monitoring of their disease status and report a feeling of relief when they are deemed free of cancer. These follow-up appointments may be conducted by their specialist nurse or with both the medical specialist and specialist nurse, and are important points of contact for the patient.

Finding 26: Reassurance – follow-up is reassuring and a safety net, particularly close to diagnosis (U)

- Illustration 55: "It is reassuring coming to the hospital because how do you know that everything is alright if you don't come?" (p.339)[53, column 1, para 4]

Finding 27: Your blood test is fine (U)

- Illustration 56: "You sort of have a normal life, although you still think of it constantly, not constantly but always there and then its...you know you feel worried having the blood test and um waiting for the result and then you're quite happy again, you've had the result and even though I don't feel ill it's just reassurance that yeah I feel fine and also I've had the blood test and that's showing I should feel fine." (p.2361)[56, column 2, para 6]
- Illustration 57: "They won't tell me what symptoms to look for which is right really, but she used to say to me, you will know if there is anything wrong, you will feel differently, and I keep thinking well I don't feel differently, as long as my blood test is fine, that to me, I'm alright." (p.2361)[56, column 2, para 6]

Category 3.3: Clinical expertise

Specialist nurses have advanced skills, knowledge and experience that place them well to manage symptoms and side effects, often without the need for medical involvement. Their clinical expertise is valued by patients who are able to have their medical needs competently attended without needing to contact their medical specialist. This may be in the form of attendance at a nurse-led clinic or a simple phone-call. If medical attention is required, the specialist nurse can arrange this in a more efficient and timely manner than the patient themselves. Often the specialist nurse is more accessible for the patient than the medical specialist and patients may be reluctant to contact their medical specialist for more minor concerns. Patients may use the specialist nurse as a sounding board to determine the need for medical intervention.

Finding 28: Management of complications (C)

- Illustration 58: "...I experienced a couple [side effects] that I wasn't, that hadn't been spoken about. I rang [FTN]. [The FTN] kept in contact with me, gave me the procedure to go through and what I should be doing so I you know I was pretty well taken care of." (p.163)[59, column 1, para 5]

Finding 29: Management of medical issues (C)

- Illustration 59:"...[the FTN] called me so she answered any questions I had about anything 'cause I was, ... I was getting a lot of diarrhoea...." (p.163)[59, column 2, para 3]

Finding 30: Readiness for discharge (C)

- Illustration 60: "I was actually quite impressed by the service itself...the short amount of time that you're in hospital that you need some sort of support network. Now I found that that...was excellent for the fact that with a phone call...,I was able to contact a health care professional who was able to give me advice and that basically is all you need when you're at home. I think you just need to talk to someone who knows what they're talking about...the fast track nurse was able to do that.....they are able to sort of look at files and know me as a person and know what I've gone through so I really don't know how it [the service] could be improved because I just found that it suited...my needs." (p.162)[59, column 1, para 6]

Table 4 below provides a summary of the findings and categories for synthesized finding 3.

ConQual summary of findings

The synthesized findings of this review were ranked according to the GRADE (Grading of Recommendations Assessment, Development and Evaluation) approach specified in the Joanna Briggs Institute Reviewers' Manual 2014.[62] This process ranked each of the three synthesized findings of this review as "moderate" as each of them were downgraded one level for both dependability and credibility. This ranking is considered a rating of "confidence" in the qualitative synthesized finding.[62] See ConQual summary of findings.

Table 4: Results of meta-synthesis 3

Synthesized finding	Category	Findings
Dependable expertise: women with gynecological cancer express trust and reassurance in the experience and expertise of the specialist nurse	Trust in the specialist nurse	• She will know - trust in the expertise of the nurse (U) • Trust in the NN – those who used NN found her to be kind and calming (U) • Feeling safe and secure (C)
	Need for reassurance	• Reassurance – follow up is reassuring and safety net, particularly close to diagnosis (U) • Your blood test is fine (U)
	Clinical expertise	• Management of complications (C) • Management of medical issues (C) • Readiness for discharge (C)

Discussion

The findings of this systematic review illustrate how women with gynecological cancer experience specialist nursing care. Three meta-synthesized findings resulted from this review: 1. Tailored care: specialist nurses play a role in understanding and meeting women with gynecological cancer's individual needs; 2. Accessible care: specialist nurses guide women with gynecological cancer along the continuum of care and are an easily accessed source of knowledge and support; and 3. Dependable expertise: women with gynecological cancer express trust and reassurance in the experience and expertise of the specialist nurse.

Categorization of the 30 findings extracted from the included studies was difficult when considering the holistic nature of the specialist nurse role. Many of the findings could have been allocated to one or more categories and likewise some categories traverse more than one synthesized finding. The illustrations were thus used for greater differentiation of the study findings. Although three of the included studies[53,54,58] specifically identified findings related to support and information provision, many of the study findings could have been allocated to the fairly general category of "source of support and information" which described many aspects of the specialist nurse role. However, those with more detailed illustrations were differentiated into more specific categories.

Individualized care is the hallmark of the specialist nurse role, requiring the nurse to assess and anticipate the needs of their patient and tailor their care accordingly. Both formal assessment and anticipation of needs through experience were identified in the study findings as means through which the specialist nurses identified women's individual needs. It was acknowledged by a patient in one study[54] that the use of a formal assessment tool by the nurse in the identification of needs helped them to identify issues that they otherwise would not have verbalized. Specialist nurses also used their experience and expertise to anticipate the needs of patients and forearm them with information. Patients appreciated being informed about what to expect from treatment. However whilst some women reported that their information needs were met, others would have liked more information or for that information to be reinforced to them. Specialist nurses should identify the patient's preferred method of receiving information and take the time to ensure that it has been understood. More than one mode of information provision may be required.

Understanding and meeting the patient's needs were further enhanced when the relationship between the woman and the specialist nurse was personalized. The women's perception that the specialist nurse had more time to spend with them afforded them the opportunity to explore concerns that they otherwise would not have broached with their medical specialists. It was through this "time" that the specialist nurse provided that a more personal, trusting relationship developed and the patient's needs were better understood. The theme of the specialist nurse being perceived to have more "time" for the patient is echoed in studies considering women with breast cancer's experience of the specialist breast nurse role. It was found that women with breast cancer believed their breast care nurse had more time available to talk to them and they were more relaxed and comfortable talking to their specialist nurse compared with their surgeon.[63,64] Some of the women in the studies included in this review also likened the relationship that they had

with their specialist nurse to a friendship. They expressed feeling at ease talking to their specialist nurse about topics they did ont feel comfortable discussing with their loved ones or medical specialists. It was also found, however, that an incompatibility of personalities of the patient and specialist nurse could preclude the development of a trusting relationship.

The accessibility of the specialist nurse formed the basis of the second synthesized finding. The women in the studies found the continuity provided by the specialist nurse convenient and reassuring. Not only did the women find it easier to discuss certain topics with their specialist nurse compared with their medical specialists, the specialist nurses were also more accessible, especially between care episodes or appointments. Care coordination and telephone access to the specialist nurse was valued by patents. Even if the patient did not access the specialist nurse, it was reassuring to them to know that they could if they needed to. Navigating their way through treatment is an onerous task for women diagnosed with gynecological cancer given that they will often require multiple treatment modalities. The specialist nurse guides the patient throughout their cancer "journey" often maintaining a relationship with the patient from diagnosis until survivorship or end of life. The value of care coordination to the patient is upheld in other studies of women with breast cancer.[65,66] They too appreciated the specialist nurses' role in managing all aspects of their care with one study describing the specialist nurse role as "paving the way through bureaucracy".[66(p.509)]

Trust in the expertise of the specialist nurse formed the basis of the third synthesized finding of the review "Dependable expertise". Women revered the knowledge and experience of their specialist nurse and were either able to have their needs met by the nurse themselves or utilize the nurse as a point of triage to gain access to medical or other intervention. The advanced level of practice of the specialist nurse also allowed them to manage the symptoms of disease or side effects of treatment effectively with minimal to no medical intervention. This created a feeling of safety and security for the patient who could rely upon the expertise of the specialist nurse. This was convenient for patients who did not have to visit their medical specialist, their GP or the emergency department. Patients valued having rapid access to a professional who knew them well. Women with breast cancer have been reported to draw on the expertise of their specialist nurse in a similar manner. In one study regarding nurse-led follow-up of breast cancer, a participant valued the expertise of her specialist nurse more highly than that of her GP in the management of her disease.[64] Another study demonstrated that women with breast cancer also utilized their specialist nurse as point of triage and relied upon them to determine the need for medical intervention.[67]

Yet easy access to expert knowledge cannot surpass the reassurance that a diagnostic test or physical examination to determine absence of disease can. The need for reassurance is high in women with gynecological cancer, with studies identifying fear of disease recurrence[24-28] and uncertainty about the future[27,29] as significant, and often unmet, needs in survivorship. Historically, follow-up aimed at detection of recurrence has been the domain of the medical specialist. However, increasingly, specialist nurses are managing the follow-up of low-risk cases of gynecological cancer and are responsible for ordering and interpreting tests to detect recurrence and delivering the results to the patient. The reassurance brought to patients by test results is mirrored in a study of nurse-led follow-up in breast cancer.[64] In this study women indicated that whilst women were satisfied with the nurse-led follow-up program, the type of follow-up (face to face or telephone) and who the follow-up was with (medical or nurse specialist) was secondary to having a mammogram every year. Thus, although the specialist nurse may be a preferred and easily accessed source of professional advice, ultimately it is disease-free status, and the tests that verify this, that women with gynecological cancer gain most solace from.

This systematic review is limited by the differences in the specialist nurse roles that were experienced by women and the timing of care provided. Some of the included studies only captured women's views during the treatment phase or the follow-up period or the specialist nurse service was only offered during these periods, whilst others considered the women's experiences of specialist nursing care throughout the entire continuum of care. Similarly, the scope of practice and purpose of the specialist nurse varied in each of the studies. This highlights the need for better definition of what a specialist nurse role is and the delineation of roles that have an advanced clinical practice focus and those that are coordination focused such as that of the nurse

navigator. Determining the appropriate qualification level for these roles is also important. This systematic review was also limited by the small number of participants in just six studies. For these reasons, comparison and validation of the women's experiences were also made with similar studies in the field of breast cancer. The purpose of this systematic review was to gain an understanding of women's experiences and perceptions of the specialist nurse role as background to a study aimed at understanding how specialist nurses contributed to the care of women with gynecological cancer in Australia and New Zealand. Yet, of the six included studies, only one was located in Australia and none in NZ. In context, however, the experiences and perceptions of women in the Australian study were comparable to those in studies from other countries, indicating that some of the needs and experiences of women with gynecological cancer are universal and may be translatable to the Australian and New Zealand contexts. It must also be considered that, all of the included studies were conducted in westernized countries, and only three provided data on the nationality of participants.[58-60] Lydon *et al.*[58] reported that all of the women in their study were of British origin and Philp *et al.*[52] reported that 10 of their 11 participants were born in Australia, though Indigenous status of those women was not recorded. Thus not only is the total number of participants' views considered through this review small, they may represent a very homogenous sample of the gynecological oncology population. Similarly, only one of the included studies[52] noted where participants lived in regard to their place of treatment. Women with gynecological cancer in Australia who live outside major cities and regional centers have poorer survival and mortality outcomes.[1] Similarly, Indigenous women in both Australia and New Zealand have lower survival rates and are more likely to die from gynecological cancer than their non-Indigenous counterparts.[1,5] This systematic review has not captured the experiences of these sub-populations.

This systematic review is further limited by the non-inclusion of the term "nurse navigator" in the search strategy. Subsequent searches of two major databases using the search term "nurse navigator" revealed the Thygesen *et al.* study[52] as the only study where gynecological oncology patients were cared for by a nurse navigator. However, a paper reporting additional findings of the Thygesen study was found.[68] The paper[68] reported on the experiences of those patients (n = 5) in the larger study[52] who used the help of the nurse navigator. This additional data and findings support the synthesized findings of this systematic review. Of particular note were the findings that the care provided by the nurse navigator up to the point of admission was helpful to patients but the cessation of the relationship thereafter was disappointing to patients.[68] This supports the synthesized finding of "Accessible care" which highlights the need for a specialist nurse to be available to patients throughout the disease trajectory. It is recommended that the term "nurse navigator" be added to the protocol for this systematic review in future revisions of this review to ensure that studies relating to this role are captured.

This qualitative systematic review compliments the quantitative review completed by Cook *et al.*[50] by capturing the women with gynecological cancers' experiences of specialist nursing care. In particular the many positive experiences of specialist nursing care analyzed in this review corroborate the high levels of satisfaction with care measured in three studies within the Cook *et al.* review.[50] This review has supported the suggestion made by Cook *et al.*[50] that specialist nurse intervention should occur at key points on the continuum of care with patients in this review reflecting positively on care from their specialist nurse at pre-diagnosis, diagnosis, during treatment and survivorship. Likewise, the positive effects measured in studies utilizing telephone contact in the review by Cook *et al.*[50] were reinforced by the comments of gratitude and reassurance relating to phone contact with their specialist nurse made by patients in studies of this review. Overall, the two systematic reviews provide an account of the specialist nurse role in gynecological oncology from the women's perspective.

Conclusion

This systematic review has synthesized the findings of seven studies that captured the experiences of women with gynecological cancer who received care from a specialist nurse. The specialist nurse offers tailored, accessible and expert care to women with gynecological cancer. Women experienced a more personal relationship with their specialist nurse that enabled the nurse to better understand and meet their needs. The provision of information and support is the hallmark of the specialist nurse role in

gynecological oncology but nurses must identify the preferred method and timing of information provision to ensure the greatest benefit to the patient. Easy, dependable access to expert care was a highly valued aspect of the specialist nurse role and a source of reassurance to the patient, so too was the continuity of care that the specialist nurse offered throughout their cancer "journey". This systematic review highlighted some of the advanced nursing practices of specialist nurses including nurse-led follow-up services and symptom and side-effect management and the positive responses of patients to these. Patients revered the specialist nurses' experience and "knowing", and utilized their nurse as a first point of contact when concerns arose.

Implications for practice

Based on the synthesized findings of this review, it is recommended that:

- Women with gynecological cancer have access to the services of a specialist nurse at key points on the continuum of care being pre-diagnosis, diagnosis, during treatment and survivorship. (Grade B)
- Specialist nurses should provide information to patients on their disease and treatment in the form preferred by the patient and ensure that this information has been understood. (Grade B)
- Specialist nurses are afforded time to spend with patients to enable greater exploration and identification of patient needs and the provision of personalized care. (Grade B)

Implications for research

This review has synthesized a small number of studies considering how women with gynecological cancer experience the care of a specialist nurse. Although there were differences in the roles and functions of the specialist nurses in the included studies and the points on the continuum of care that they had contact with the patient, the patients' experiences were largely positive across the six studies. Many of these positive experiences are paralleled in similar studies of the breast cancer population. When considered with the results of the review by Cook *et al.*,[50] this review provides an account of the women's perspective of the specialist nurse role in gynecological oncology that justifies the inclusion of this role in the treatment team of women with gynecological cancer. It is recommended that further studies are conducted that evaluate and explore the experiences of women under the care of specialist nurses in order to expand this small body of evidence. This research should seek the perspectives of women of culturally and linguistically diverse backgrounds and Indigenous populations as they appear to be underrepresented in current research. In Australia and New Zealand, Indigenous women with gynecological cancer experience significantly poorer clinical outcomes than women of non-Indigenous status[1,5] and their access to, and experience of, specialist nursing care should be determined. It is also recommended that the experiences and perceptions of other key stakeholders in the specialist nurse role be sought in order to further evaluate the role as their views have not been captured to date. The specialist nurses themselves and the health professionals that interface with their role including medical, allied health, nursing and research staff should be engaged with the aim of determining all aspects of the contribution of specialist nurses to the care of women with gynecological cancer.

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Appendix I: Appraised articles and reason for inclusion/exclusion

Record no.	Citation	Database	Appraised by	Included? Y/N/Unsure	2nd review MM/SL/KR	Included after 2nd review Y/N	Included after 3rd review? Y/N	Comments/rationale
75	Thygesen MK, Pedersen BD, Kragstrup J, Wagner L, Mogensen O. Gynecological cancer patients' differentiated use of help from a nurse navigator: a qualitative study. BMC Health Services Research. 2012;12:168-.	CINAHL	OC	Y	SL	Y	N/A	Study meets inclusion criteria
176	Lloyd PA, Briggs EV, Kane N, Jeyarajah AR, Shepherd JH. Women's experiences after a radical vaginal trachelectomy for early stage cervical cancer. A descriptive phenomenological study. European Journal of Oncology Nursing. 2014;18 (4):362–71.	CINAHL	OC	Y	MM	Y	N/A	Study meets inclusion criteria
201	Jefferies H. Ovarian cancer patients: are their informational and emotional needs being met? Journal of Clinical Nursing. 2002;11 (1):41–7.	CINAHL	OC	N	MM	Y	N (KR)	Study excluded due to insufficient qualitative data presented, mainly quantitative.
219	Guest A, Manderville H, Thompson R. Developing a clinic to meet patients' preoperative needs. Cancer Nursing Practice. 2012;11 (3):25–9.	CINAHL	OC	N	MM	Y	Y (KR)	Although this paper was assessed as low-moderate quality with poor description of methodology, the translation of findings to practice is strong and has therefore been included.
833	Kelly DF, Faught WJ, Holmes LA. Ovarian cancer treatment: the benefit of patient telephone follow-up post-chemotherapy. Canadian oncology nursing journal = Revue canadienne de nursing oncologique. 1999;9 (4):175–8.	PubMed	OC	N	SL	N	N/A	Excluded as quantitative study, no qualitative analysis of open-ended questions.
896	Cox A, Faithfull S. Aiding a reassertion of self: a qualitative study of the views and experiences of women with ovarian cancer receiving long-term nurse-led telephone follow-up. Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer. 2015.	PubMed	OC	Y	MM	Y	N/A	Study meets inclusion criteria
1049	Steginga SK, Dunn J. Women's experiences following treatment for gynecologic cancer. Oncology nursing forum. 1997;24 (8):1403–8.	Scopus	OC	N	SL	N	N (SL)	A descriptive quantitative study, insufficient qualitative data presented to enable inclusion.

(*Continued*)

Record no.	Citation	Database	Appraised by	Included? Y/N/Unsure	2nd review MM/SL/KR	Included after 2nd review Y/N	Included after 3rd review? Y/N	Comments/rationale
1307	Lydon A, Beaver K, Newbery C, Wray J. Routine follow-up after treatment for ovarian cancer in the United Kingdom (UK): Patient and health professional views. European Journal of Oncology Nursing. 2009;13 (5):336–43.	Scopus	OC	Y	SL	Y	N/A	Study meets inclusion criteria
1736	Carlsson ME, Strang PM. Educational support programme for gynaecological cancer patients and their families. Acta Oncologica (Stockholm, Sweden). 1998;37 (3):269–75.	Manually sourced	OC	N	MM	Y	N (SL)	Excluded due to results relating to women's experiences of the support group. Although the specialist nurse arranged the support group the participants speak of their experiences with the other participants, not the nurse. Limited discussion of qualitative method and limited analysis of qualitative data.
1737	Philp, S., Carter,J., Carnett, C., D'Abrew, N., Pather, S. & White, K. Patient's Perspectives of Fast-Track Surgery and the Role of the Fast-Track Clinical Nurse Consultant in Gynecological Oncology. Holistic Nursing Practice. 2015: 29 (3):158–166.	Manually sourced	OC	Y	SL	Y	N/A	Study meets inclusion criteria
1835	Kobleder A, Mayer H and Senn B. 'Feeling someone is there for you' - experiences of women with vulvar neoplasia with care delivered by an Advanced Practice Nurse. J Clin Nurs. 2017; 26: 456–65.	CINAHL	OC	Y	SL	Y	N/A	Study meets inclusion criteria

Appendix II: Characteristics of included studies

Study	Methodology	Method	Phenomenon of Interest	Setting and country	Participants	Authors, conclusions
Thygesen, Pedersen, Kragstrup, Wagner & Mogensen, 2012.	Longitudinal, hermenuetic phenomenological study	Semi-structured interviews, semi-structured participant diaries, interviewer observations.	Exploration of who may benefit from a nurse navigator (NN) and the meaning of patients experiences with the NN.	Gynaecological surgical unit of Odense University Hospital, DENMARK.	21 women with gynaecological cancer Age range 36–79 Ovarian (n = 10) Uterine (n = 6 Cervical (n = 5) Surgery (n = 11) Partnered (n = 19) Live alone (n = 2)	Not all participants wanted/used help offered by NN. Those who had a close friend/relative who was a healthcare professional or those who trusted their physician didn't access their NN. NN offered a new trusting relationship to those without such person to trust.
Lloyd, Briggs, Kane, Jeyarajah & Shepherd, 2014.	Descriptive phenomenological study	In-depth telephone interviews	The lived experience of women up to ten years after a radial trachelectomy focussing on health, fertility, sexuality and longer term supportive care needs.	Two NHS hospitals, UK.	12 women with cervical cancer who had undergone trachelectomy surgery 1–10 years prior 29–45 years old	The clinical nurse specialist was identified as a source of support for the women.
Guest, Manderville & Thompson, 2012.	Not stated	Focus groups (pre & post) and questionnaire.	Evaluation of a CNS-led pre-admission clinic for women undergoing surgery for suspected gynaecological malignancy.	Queen Elizabeth Hospital, UK	19 women attended supportive care clinic Pre-intervention focus group (n = 5) Post-intervention focus group (n = 5) Questionnaire (n = 12) No demographic or clinical characteristics data collected	Patients benefit from one-to-one discussions with a CNS prior to surgery.
Cox & Faithfull, 2015.	Interpretive phenomenological study	In-person or telephone semi-structured interviews	Exploration of the views and experiences of women with ovarian cancer who had received long term (>3 years) nurse-led telephone follow-up.	Surrey Cancer Centre, UK.	11 women with stage I-III ovarian cancer At least 3 years telephone follow up Aged 47–79	The CNS led telephone follow up offered women a consistent and constant source of support that enabled a reassertion of self and rejection of identity as a patient in cancer survivorship

(*Continued*)

Study	Methodology	Method	Phenomenon of Interest	Setting and country	Participants	Authors, conclusions
Lydon, Beaver, Newbery & Wray, 2009.	Symbolic interactionism	Patient focus group Health professional focus group	Perceptions of patients and health care professionals on current follow-up services following treatment for ovarian cancer	Large oncology hospital in Machester, UK.	Patients with ovarian cancer, not currently undergoing treatment (n=6) Aged 52–73 6 months – 10 years post treatment Health professionals: (n=7)	Follow up services should be tailored to meet individual needs and preferences. Patients placed importance on detecting disease recurrence at follow-up.
Philp, Carter, Carnett, D'Abrew, Pather & White, 2015.	Philosophical perspective not stated	Semi-structured interviews; face to face or via telephone.	Experiences of fast-tracked gynecological oncology patients in relation to the care provided to them by a Fast-Track Nurse.	Royal Prince Alfred Hospital, Sydney, Australia.	Patients who were part of the fast-track program between January 2010 and July 2011 with gynecological cancer or a complex benign gynecological condition.	High level of patient satisfaction with the unique service provided by the fast-track nurse. The fast-track nurse offered timely and tailored support to patients and coordinated their care.
Kobleder, Mayer& Senn, 2016.	Qualitative methodology, philosophical perspective not stated.	Narrative interviews – unclear as to whether these were face-to-face or telephone interviews.	Experiences of women with vulvar neoplasia who received care from an Advanced Practice Nurse (APN)	Multiple gynaecological cancer treatment centres in Switzerland.	N=13 women with VIN or vulvar cancer. 6–16 months post treatment Aged 49–84 years	Women with vulvar neoplasia experienced care delivered by an APN as 'feeling someone is there for you'. Psychosocial support from the APN beyond surgery was important to the participants.

Summary

The systematic review provided the perspective of women with gynaecological cancers cared for by specialist nurses. The review complements a quantitative systematic review considering the effectiveness of specialist nursing interventions on quality of life, satisfaction with care and psychological outcomes of women with gynaecological cancers (Cook et al., 2015). The systematic review found that women with gynaecological cancers valued individualised care, tailored to meet their needs, corroborating the findings of Cook et al. (2015) who showed that comprehensive care from specialist nurses were most successful in affecting quality of life, satisfaction with care and psychological outcomes.

Chapter 3 – Integrative review

Introduction

This chapter includes an integrative review of the needs of women with gynaecological cancers. This body of literature was originally reviewed as part of the background to the study though over the course of this study it continued to expand, and a decision was made to perform an integrative review. While the systematic review included in Chapter 2and the previous quantitative systematic review completed by Cook et al. (2015) provide the women's perspective of specialist nursing care, neither the reviews nor the studies within them consider or measure the needs of women with gynaecological cancers. The review by Cook et al. (2015) speculated that the measurements used to determine effectiveness of specialist nurse care such as quality of life may not be sensitive to this. Identifying the needs of women with gynaecological cancers is integral to determining the role that specialist nurses play in the care of women with gynaecological cancers and may also be a way of measuring the effectiveness of specialist nursing care. The integrative review utilised tools and guidelines from the JBI Reviewer's Manual (Aromataris & Munn, 2017) and was submitted for publication to the Journal of Clinical Nursing and is currently under review. The protocol for this review was published on the PROSPERO register of systematic reviews No: CRD42017064993 accessed at https://www.crd.york.ac.uk/PROSPERO. The final review deviated from the protocol in the exclusion of one research question relating to how needs are met, as no included studies investigated this, and the combination of two other questions into one. The integrative review was the second of two literature reviews undertaken as part of this study. Together the two literature reviews integrate the experiences of women with gynaecological cancers of specialist nursing care with their needs to provide a limitedunderstanding of how specialist nursing care can, and does, contribute to the care of women with gynaecological cancers.

Integrative review

JCN Journal of Clinical Nursing

The needs of women with gynaecological cancer across their disease trajectory – an integrative review

Journal:	*Journal of Clinical Nursing*
Manuscript ID	JCN-2018-0048
Manuscript Type:	Review
Keywords:	Cancer, Needs, Review, Women's Health, Health Needs Instrument, Information Needs, Oncology Nursing, Patient-Centred Care

Title

The needs of women with gynaecological cancer across their disease trajectory – an integrative review.

Abstract

Aims and objectives: To synthesise the literature relating to the needs and unmet needs of women with gynaecological cancer who had access to treatment for their cancer. This review also aimed to determine women's needs at each phase of their disease, the needs that were common and specific to women with each gynaecological cancer type, and the tools utilised to measure needs.

Background: In countries where funding and resources are available for the treatment and care of women with gynaecological cancer, these resources should be directed to the areas that best meet the needs of the patient.

Design: Integrative review of quantitative and qualitative studies.

Methods: 13 major databases were searched between 2007 and 2017 and the reference lists of relevant papers hand-searched. Inclusion criteria were applied in the selection of studies for this review. Studies meeting inclusion criteria were subject to a critical appraisal including a risk of bias assessment where applicable. Data were extracted and a comparative, narrative analysis performed.

Results: A total of 25 studies consisting of nine qualitative and 16 quantitative studies, including a total of 2992 participants, were considered in this review. Seven different quantitative tools were utilised by included studies to measure needs or unmet needs. Women with all gynaecological cancers needed help to manage fears of recurrence and spread of disease, uncertainty about their future, and reported several common informational and practical needs across their disease trajectory.

Conclusions: The needs of women with gynaecological cancer were identified across the trajectory of their disease. Many needs identified were common to all gynaecological cancer types with only a few needs specific to given cancer types.

Relevance to clinical practice:

The identification of needs and unmet needs is integral to the provision of holistic, timely, and individualised care to women with gynaecological cancer.

Key words

Female genital neoplasms; needs assessment; cancer survivors; oncology nursing; patient-centred care; women's health; ovarian cancer; cervical cancer; endometrial cancer; vulval cancer.

Impact statement

What does this paper contribute to the wider global clinical community?

- This review synthesises current literature on the needs of women with gynaecological cancer in developed nations who have access to comprehensive treatment of their disease.
- This review provides a summary of common and specific needs of women with each gynaecological cancer type, at each phase of their disease.

Introduction

Gynaecological cancer is a collective term for cancers of the female reproductive system including cancers of the cervix, endometrium, ovaries, vagina, vulva and fallopian tubes (Cancer Australia, 2013a). Together cancers of the cervix, endometrium and ovary account for approximately 17% of all cancers affecting women worldwide (Ferlay et al., 2015). The incidence of each of the gynaecological

cancer varies greatly in developed and developing nations and global data is not available for cancers of the vulva, vagina or fallopian tubes (Ferlay et al., 2015).

Worldwide, cervical cancer is the fourth most common cancer in women with around 85% of this burden occurring in less developed regions (Ferlay et al., 2015). The age standardised incidence of cervical cancer is highest in East Africa, estimated at 42.7 per 100,000 (Ferlay et al., 2015) and cervical cancer is the most common cause of cancer related death in women in Sub-Saharan Africa (Denny et al., 2013). This compares with much lower rates of cervical cancer incidence in Australia and New Zealand (5.5 per 100,000) and Western Asia (4.4 per 100,000) (Ferlay et al., 2015).

Cervical cancer screening programs introduced in both New Zealand and Australia in 1990 and 1991 respectively have halved the incidence and mortality rates of cervical cancer in these countries (Australian Institute of Health and Welfare, 2016; New Zealand Ministry of Health, 2008). The introduction of Human Papilloma Virus (HPV) vaccines, able to protect against the strains of HPV responsible for 70-80% of cervical cancers, has meant that cervical cancer is now a largely preventable disease (Australian Institute of Health and Welfare, 2016). However nations where cervical cancer poses the greatest burden do not have the capacity to vaccinate, screen or treat the disease and incidence is expected to rise further over the next 20 years (Ali, Kuelker, & Wassie, 2012; Denny et al., 2013).

In contrast, ovarian and endometrial cancers are more prevalent in developed nations. Incidence of ovarian cancer per 100,000 females in less developed regions is 4.9 compared with 9.1 in more developed regions (Ferlay et al., 2015). Endometrial cancer affects 14.7 in 100,000 women in developed regions compared with 5.5 per 100,000 women in developing regions (Ferlay et al., 2015). Despite access to treatment in developed nations, the risk of death before the age of 75 from ovarian or endometrial cancer is 60% and 30% respectively in developed areas of the world, compared with 30% and 20% in developing regions (Ferlay et al., 2015). Whilst endometrial cancer

is highly treatable, as indicated by the higher survival rates, ovarian cancer is often not diagnosed until its later stages due to its vague symptoms which contributes to poorer survival rates (Australian Institute of Health and Welfare & Cancer Australia, 2012). Methods of screening or early detection tests are not currently available for either endometrial or ovarian cancer (Australian Institute of Health and Welfare & Cancer Australia, 2012).

This review will focus on women with gynaecological cancer living in developed nations who have access to treatment of their disease. The needs and unmet needs of women with gynaecological cancer living in developing nations, where treatment for gynaecological cancer is scarce or not routinely available, are likely to differ greatly from those with access to treatment. This review intends to provide an account of the needs of women with gynaecological cancer who have access to treatment, in order to inform the health professionals and health services that provide such treatment. In countries where funding and resources are available for the treatment and care of women with gynaecological cancer, these resources should be directed to the areas that best meet the needs of the patient. In particular, this integrative review will inform a study considering the role of specialist nurses in the care of women with gynaecological cancer and adds to the knowledge gained through previous systematic reviews relating to specialist nursing care of women with gynaecological cancer (Cook, McIntyre, & Recoche, 2015; Cook, McIntyre, Recoche, & Lee, 2017).

Aims

The aim of this integrative review is to synthesise the literature relating to the needs and unmet needs of women with gynaecological cancers across their disease trajectory. This integrative review addressed the following questions:

1. What are the needs and unmet needs of women with gynaecological cancer at key points on their disease trajectory: Pre-diagnosis/diagnosis, surgical treatment, chemotherapy/radiotherapy treatment, post-treatment/survivorship, disease recurrence and end of life?
2. What are the specific and common needs and unmet needs of women with each of the gynaecological cancer types?
3. What tools are used to identify the needs and unmet needs of women with gynaecological cancer?

Methods

The protocol for this review can be accessed via the PROSPERO register of systematic reviews No: CRD42017064993 accessed at https://www.crd.york.ac.uk/PROSPERO. The final review deviated from the protocol in the exclusion of one research question relating to how needs are met, as no included studies investigated this, and the combination of two other questions into one.

Criteria for inclusion

Types of studies

Qualitative, quantitative and mixed methods primary research were considered for inclusion in this review. Systematic reviews of qualitative, quantitative or mixed method research were also considered for inclusion. Published papers and grey literature were considered for inclusion though conference abstracts without corresponding papers were excluded. Published literature expressing expert opinion or non-systematic literature reviews were not considered for inclusion.

Types of participants

Studies including women with a primary diagnosis of gynaecological cancer including cancer of the uterus/endometrium, ovary, cervix, vagina, vulva or fallopian tube who had access to treatment for their disease were considered for inclusion in this integrative review. Study participants may have been at any point on their disease trajectory including but not limited to: pre-diagnosis, diagnosis,

surgical treatment, chemotherapy treatment, radiotherapy treatment, survivorship, disease recurrence, palliative care or end of life. Studies including patients with gynaecological cancer and other cancers or conditions were considered for inclusion if abstraction of findings pertaining to the gynaecological cancer participants only was possible.

Phenomenon of Interest

Studies that explored the needs or unmet needs of women with gynaecological cancer were considered for inclusion in this review. Studies exploring women's experiences of gynaecological cancer were only included where the study explicitly identified the women's needs. Systematic reviews of such studies were also considered for inclusion.

Types of interventions and outcome measures

Primary studies evaluating an intervention relating to the needs of women with gynaecological cancer were considered for inclusion in this review. Studies measuring needs and unmet needs or exploring women's experiences in relation to needs and unmet needs were considered for inclusion. Systematic reviews of such studies were also considered for inclusion.

Context

This review considered studies conducted in developed nations where comprehensive treatment for gynaecological cancer is offered. The settings in which the primary studies were conducted may have included, but were not limited to: acute hospitals, outpatient/ambulatory clinics, chemotherapy or radiotherapy units, support groups, palliative care units or the woman's home.

Search strategy

The search strategy aimed to find both published and unpublished primary studies and published systematic reviews. Databases to be searched are: CINAHL, MEDLINE, Cochrane Database of Systematic Reviews, Joanna Briggs Institute EBP Database, PsychINFO, AMED, EMBASE, ProQuest,

ProQuest Dissertations and Theses Global, Thesis Canada, Bielfield Academic Search Engine (BASE), Open Access Theses and Dissertations (OATD) and Caresearch. A hand search of the reference list of relevant articles was also conducted. The search was limited to studies published in English as the authors comprehend English only. The search was also limited to studies published between 2007 and 2017. This 10 year time frame was selected to ensure that identified needs were reflective of current approaches to diagnosis and treatment of the gynaecological cancers given that advances in these areas have improved survival rates in recent years (AIHW, 2012). The search was completed on July 28, 2017.

Search terms were combined with 'OR' within each group and the results of each group combined with 'AND'. Gynaecological cancer term search: 'Cancer' OR 'Tumo?r' OR 'malignancy' OR 'neoplasm' AND 'Gyn?ecolog*' OR 'Cervi*' OR 'Ovar*' OR 'Uter*' OR 'Endometri*' OR 'Vulva#' OR 'Vagina#' OR "Fallopian tube". Needs term search: 'need#' OR 'experience#' OR "supportive care" OR "quality of life"

Quality appraisal and risk of bias

Papers meeting the inclusion criteria were assessed for methodological quality and risk of bias utilising the critical appraisal tools for assessment of qualitative, quantitative and systematic review studies from the Joanna Briggs Institute Reviewers Manual (Aromataris & Munn, 2017). All studies meeting the inclusion criteria were appraised by the primary author and verified by the second and third authors. Where three or more critical appraisal criteria were determined to be a 'no' or 'unclear' the article was appraised by a second reviewer and a decision on the inclusion of the study based on methodological quality was made. If discrepancy arose between the appraisals of the two reviewers, a third reviewer appraised the paper and a final decision was made. Studies had to meet a minimum of six of the relevant Joanna Briggs Institute critical appraisal criteria to be included in this review.

Data Extraction

Data were extracted from papers selected for inclusion using customised versions of the data extraction tools for qualitative and quantitative studies from the Joanna Briggs Institute Reviewers Manual (Aromataris & Munn, 2017). Data extraction was completed by the primary author and verified by a second reviewer.

Data Synthesis

As this review included both qualitative and quantitative studies a narrative analysis was conducted to integrate the identified evidence. A constant comparison approach, as described by Whittemore and Knafl (2005), was employed to analyse the extracted data from the diverse methodologies of the included papers. Data relating to needs and unmet needs from the included studies were classified according to the tumour type of the participant and the stage on the disease trajectory that the need occurred.

Results

Search results

The search strategy yielded 1445 papers for review. As shown in Figure 1 the PRISMA flowchart of the study selection and inclusion process, a total of 25 studies were included in this review after the processes of reviewing title and abstract, review of full text and quality appraisal were complete. Many studies included 'needs' in the title but utilised measures such as 'quality of life' or 'distress' rather than specific tools measuring needs or unmet needs and were thus excluded. Some studies were excluded as they were conducted in developing countries. Two systematic reviews were excluded upon consideration of the full text (Maguire, Kotronoulas, Simpson, & Paterson, 2015;

Roland, Rodriguez, Patterson, & Trivers, 2013). Maguire et al. (2015) was excluded on the basis that it included studies from developing nations. The other excluded systematic review (Roland et al., 2013) included only two studies that specifically measured needs or unmet needs. These two studies were thus included individually in this review (Kornblith et al., 2010; Matulonis et al., 2008).

[Insert Figure 1 here]

Methodological quality of studies

The methodological quality of studies was rated as 'High' if they met eight or more criteria of the relevant critical appraisal tool of the Joanna Briggs Institute Reviewers Manual (Aromataris & Munn, 2017); 'Medium' if they met six to seven criteria; and 'Low' if they met five or less criteria and were subsequently excluded. The overall quality rating of the 25 included studies is noted in the 'Appraisal' section of Table 1 Characteristics of included studies. Eight of the included studies were assessed at the 'medium' level and 17 studies were assessed to be of 'high' methodological quality. Four of the 29 studies critically appraised were categorised as 'no' or 'unclear' for five or more criteria on the relevant Joanna Briggs Institute critical appraisal tool and were confirmed to be unsuitable for inclusion by second and third reviewers (Dahl, Wittrup, Væggemose, Petersen, & Blaakaer, 2013; Hill et al., 2011; McCallum et al., 2014; Simonelli & Pasipanodya, 2014). The criteria that the four excluded studies did not satisfactorily meet related to sample and sampling issues, reliability and validity of tools used, and reporting of methods.

Characteristics of included studies

This integrative review included a total of 25 studies consisting of nine qualitative and 16 quantitative studies. No mixed-method studies or systematic reviews met the inclusion criteria. Details of the design of each study included in this review are presented in Table 1 under the section 'Study details' which lists the purpose and setting, methods, and sample size of each study. The

characteristics of the participants from each of the included studies are also presented in Table 1 including the time since diagnosis, tumour type and phase of disease.

[Insert table 1 here]

Settings

Studies included in this review were conducted in countries across Europe, North America and Australasia mostly within or via healthcare settings providing in-patient or out-patient gynaecological cancer care. Some studies were instigated via government databases or larger study databases. One study was set in South Africa and although this nation can be considered both 'developed' and 'developing', it was included on the basis that it was studying women who were receiving treatment for their cancer.

Sample size

Overall the 25 studies considered in this review included 22 different cohorts of women representing a total of 2992 participants. The 16 quantitative studies sampled from 13 different cohorts of women with a total of 2845 participants. The papers by Beesley, Janda, Eakin, Obermair, and Battistutta (2007) and Beesley et al. (2008) included participants from the same cohort of gynaecological cancer survivors and the papers from Beesley et al. (2015) and Rowlands, Janda, McKinnon, Webb, and Beesley (2015) included participants from the same cohort of endometrial cancer survivors. Fitch and Steele (2010) presented the results of the subsample of ovarian cancer patients from a larger study including women with all gynaecological cancer types also included in this review (Steele & Fitch, 2008). A total of 147 women participated in the nine qualitative studies included in this review.

Time since diagnosis and phase of disease

The amount of time since diagnosis was reported by n=21 studies. As some studies reported time since diagnosis as a mean score and others reported on range, an overall mean time since diagnosis for all participants in the included studies could not be calculated. The time since diagnosis and

phase of disease for the participants of each of the included studies is presented in Table 1. Participants of the studies included in this review were at various phases of their gynaecological cancer when they participated in each study. The majority of studies in this review (n=19) included women during the survivorship phase of their disease, with 13 studies researching only women in this phase. Three studies (n=3) investigated women's needs before or at the point of diagnosis and seven (n=7) of the included studies considered women's needs while receiving treatment for their gynaecological cancer. The needs of women with recurrent disease were examined in three (n=3) studies and only one study considered the palliative care needs of women with gynaecological cancer. One study did not report on the phase of disease that participants were at during the study (Baldwin & Usher, 2008).

Cancer type

The gynaecological cancer type that the participants of each study were diagnosed with is noted in Table 1. Two studies with a total of 13 participants did not specify which gynaecological cancer type participants were diagnosed with, thus total participant numbers for each cancer type cannot be calculated for this review. The remaining 2,979 participants across 23 studies were diagnosed with the following tumour types: Cervical n= 401; Ovarian n= 1,182; Uterine/Endometrial n= 1,162; and Vulval/Vaginal/Other n= 234. Eleven of the studies included in this review researched women with all types of gynaecological cancer. Other included studies specifically researched women with a particular cancer type: ovarian cancer (n=7); endometrial cancer (n=2); cervical cancer (n=1); and vulval cancer (n=1). One study included women with cervical and endometrial cancer.

Needs and unmet needs of women with gynaecological cancer at given stages of the disease trajectory

The needs and unmet needs of women with gynaecological cancer, as identified by the included studies, were analysed according to the phase of disease the participants were in at the time the

research was conducted. Some needs identified by women may have related to an earlier phase than the one during which they were investigated. In this case the needs have been recorded under the phase that they were collected, but specify when the need existed. Definitions of the terms used relating to the phases of disease and the categorisation of needs is provided in Table 2. The needs analysed in this review were those ranked highest by participants as reported in the quantitative studies, for example the 'top five' or 'top ten' needs, and all needs reported in the qualitative studies. Sixteen of the 25 studies included in this review researched women in one specific disease phase, eight studies including women at more than one phase, and one study not specifying the phase that their participants were at on the disease trajectory (Baldwin & Usher, 2008). Two studies did however present discreet data on women in the different disease phases (Gleeson et al., 2013; Jeppesen, Mogensen, Dehn, & Jensen, 2015). Table 3 presents the studies which included women at each of the phases of disease. Studies listed in bold are those which included women only in the identified phase or which provided discreet data for women at different phases. Where studies included women at more than one phase of disease the study is listed in all applicable phases. Table 4 provides a summary of the categorised needs and unmet needs for each disease phase identified by those studies only including women at the given disease phase. Where studies traversed more than one phase, the findings of such studies are included in the narrative analysis for each relevant phase included below.

[Insert Table 2 here]

[Insert Table 3 here]

Needs and unmet needs of women during the pre-diagnostic/ diagnostic period

Only one study included in this review exclusively considered the needs of women with gynaecological cancer during the pre-diagnostic/diagnostic phase of their disease (Holt, Hansen, & Mogensen, 2014) and another study presented discreet data for this phase (Jeppesen et al., 2015).

An additional study investigated the needs of women in the pre-diagnostic/diagnostic phase of their gynaecological cancer along with those in the survivorship and disease recurrence phases (Papadakos et al., 2012).

The qualitative study by Holt et al. (2014) identified that women with gynaecological cancer wanted information about testing, their disease and treatment during the pre-diagnostic period and also wanted an overview of the pre-diagnostic period. Patients in the study were concerned for the impact that their pending diagnosis would have on their loved ones and in some cases concealed their situation from them during the pre-diagnostic period (Holt et al., 2014). Managing the psychological effects of a possible cancer diagnosis, such as anxiety, during the pre-diagnostic/diagnostic period was also a need identified by participants in the study by Holt et al. (2014).

The two quantitative studies which also included women at the pre-diagnostic/diagnostic phase, utilised different tools to measure needs but reported findings similar to that of Holt et al. (2014). Jeppesen et al. (2015) utilised the Three-level Needs Questionnaire (3LNQ) to determine the priority needs of cervical and endometrial cancer patients at diagnosis. Endometrial and cervical cancer patients identified the same four out of five priority problems at diagnosis (though ranked them differently): worry about the future, treatment and side effects; focus on getting well; psychological/emotional issues and the practical aspects of treatment such as transportation, and returning to work (Jeppesen et al., 2015). 'Fatigue' was a top five problem for cervical cancer patients in that study, replaced by 'bleeding and discharge' for the endometrial cancer participants. These results were similar to those found by Papadakos et al. (2012) who looked at the informational needs of women with gynaecological cancer, n=68 (37.8%) of whom were newly diagnosed. Utilising a researcher-designed tool they found that participants wanted information relating to: side effects of treatment; the likelihood of cure; different treatments; symptoms of

disease; general information about cancer; risks for family members; management of pain, fatigue and nausea and vomiting; and coping with fear of recurrence.

[Insert Table 4 here]

Needs and unmet needs of women during treatment

One study exclusively considered the needs of women during the treatment phase for cervical cancer (Long, Friedrich-Nel, & Joubert, 2016) and two others presented discreet data for women receiving treatment along with those in other phases (Gleeson et al., 2013; Jeppesen et al., 2015). However an additional three studies included women who were receiving treatment for their disease along with woman at other phases of their gynaecological cancer without presenting the data for each phase separately (Beaver & Booth, 2007; Fitch & Steele, 2010; Steele & Fitch, 2008). Four studies were quantitative and utilised three different tools (SCNS; 3LNQ; INQ) to determine the needs of women in this phase (Beaver & Booth, 2007; Fitch & Steele, 2010; Jeppesen et al., 2015; Steele & Fitch, 2008). Two studies considered women's needs during this phase of disease utilising a qualitative approach (Gleeson et al., 2013; Long et al., 2016). The studies indicate that this phase is a time where information needs are prominent for women with gynaecological cancer. The women who were receiving treatment during the studies wanted printed information, in their preferred language, to accompany verbal explanation of their treatment, what it involved, its side effects and late effects, the likelihood that it would cure them, and an overview of the overall treatment plan (Beaver & Booth, 2007; Long et al., 2016). Women with ovarian cancer specifically needed to know their options in regard to treatment focused genetic testing (TFGT), wanted this information to be delivered before surgery or chemotherapy, and to be delivered face-to-face by a medical oncologist with supporting, simple written material (Gleeson et al., 2013). Physical needs relating to treatment emerged during this phase including fatigue, urological issues, sexual issues and needs related to lymphoedema for women with endometrial and cervical cancer (Jeppesen et al., 2015; Long et al., 2016). The psychological needs of women receiving treatment for a gynaecological cancer related to

fear of recurrence, spread of the cancer,and feelings of uncertainty about the future (Fitch & Steele, 2010; Steele & Fitch, 2008). Table 4 includes a summary of the needs identified by women during the treatment phase of their disease.

Needs and unmet needs of women during survivorship

A significant number of studies have measured the needs of gynaecological cancer survivors in recent years, of which 19 have been included in this review. Thirteen of these studies focused specifically on women's needs during the survivorship phase and one study presented discreet data relating to this phase. A summary of their findings is included in Table 4. The remaining five studies including gynaecologcial cancer survivors are discussed in the following narrative analysis. With improvements in treatment options, survival rates for gynaecological cancer have also improved with more women living in the 'survivorship' phase of their disease. Included studies were not homogenous in regards to tools used and sample characteristics to allow a meta-analysis, however the included studies do support each other in their findings.

Women with all types of gynaecological cancer continued to have informational needs during the survivorship phase and the most common needs related to knowing the signs and symptoms of disease recurrence or spread (Beaver & Booth, 2007; Olesen et al., 2015; Walton, Reeve, Brown, & Farquhar, 2010). Being informed that the cancer was under control and diminishing was also important to women at this time (Beesley et al., 2013). Women also wanted information to help them make lifestyle changes and get themselves well again (Beaver & Booth, 2007; Beesley et al., 2013; Walton et al., 2010). With the benefit of hindsight, women identified that they needed more information about the effects of treatment on fertility (McCallum, Lefebvre, Jolicoeur, Maheu, & Lebel, 2012) and more generally the nature and effects of treatment (Beaver & Booth, 2007; Papadakos et al., 2012) in a form that they could understand (Hodgkinson et al., 2007). Similarly,

women needed more information about the causes, prevention and treatment of lymphoedema (Beesley et al., 2007; Beesley et al., 2015). Although identified by women in the survivorship phase, these needs would have been best met during the diagnostic and treatment phases of the women's disease. In addition to needing to know that they were receiving the best medical care (Hodgkinson et al., 2007; Ploegsma, 2016; Rowlands et al., 2015; Walton et al., 2010), women also wanted access to complimentary and alternative therapies during the survivorship period (Hodgkinson et al., 2007; Ploegsma, 2016; Rowlands et al., 2015; Walton et al., 2010)

There was a high level of practical needs among survivors with gynaecological cancer in the studies included in this review. As survivorship is a phase where active treatment stops and frequent contact with the healthcare system ceases, women reported that they wanted a central contact within the healthcare system that they could speak to if they had any concerns (Beesley et al., 2013; Ploegsma, 2016; Urbaniec, Collins, Denson, & Whitford, 2011; Walton et al., 2010). The women needed to know that their doctors were talking to each other to coordinate their care (Hodgkinson et al., 2007; Ploegsma, 2016; Rowlands et al., 2015; Urbaniec et al., 2011) and to feel like they were managing their health together with the healthcare team (Hodgkinson et al., 2007; Ploegsma, 2016; Rowlands et al., 2015). Participants of the included studies also desired their follow-up care during survivorship to be holistic and not focused on detecting recurrence alone (Beesley et al., 2013; McCallum et al., 2012; Olesen et al., 2015; Philp, Mellon, Barnett, D'Abrew, & White, 2017; Walton et al., 2010). The practical needs of gynaecological cancer survivors also included local access to health services (Hodgkinson et al., 2007; Ploegsma, 2016; Rowlands et al., 2015) and better hospital parking (Hodgkinson et al., 2007; Rowlands et al., 2015). Beesley et al. (2007) and Beesley et al. (2015) specifically investigated women's needs in regards to lymphoedema and found that they required help in managing the symptoms of lymphoedema in their workplaces, had difficulty completing daily

activities due to their lymphoedema and also had difficulty with the costs of lymphoedema management, a finding also supported by Philp et al. (2017).

The physical effects of treatment continued for women into the survivorship period and study participants required help to manage: fatigue (Beesley et al., 2008; Beesley et al., 2013; Fitch & Steele, 2010; Steele & Fitch, 2008; Walton et al., 2010); not being able to do the things they used to do (Beesley et al., 2008; Fitch & Steele, 2010; Steele & Fitch, 2008) and other ongoing side-effects and complications of treatment (Ploegsma, 2016; Rowlands et al., 2015). Women with lymphoedema needed help to manage the associated symptoms and also needed assistance to manage leg pain and discomfort caused by lymphoedema (Beesley et al., 2007; Beesley et al., 2015; Philp et al., 2017; Walton et al., 2010). Other symptoms and side effects reported by women for which they needed help included altered urinary function (Philp et al., 2017), menopausal symptoms and vaginal changes (Walton et al., 2010).

Psychologically and emotionally the effects of gynaecological cancer extended into the survivorship period. Managing fear of cancer recurrence and spread of disease were prominent needs for women in this phase (Beesley et al., 2008; Beesley et al., 2013; Fitch & Steele, 2010; Hodgkinson et al., 2007; Papadakos et al., 2012; Ploegsma, 2016; Rowlands et al., 2015; Steele & Fitch, 2008; Urbaniec et al., 2011; Walton et al., 2010). Women in the studies included in this review also reported a need to manage feelings of uncertainty about the future (Beesley et al., 2008; Beesley et al., 2013; Fitch & Steele, 2010; Rowlands et al., 2015; Steele & Fitch, 2008; Walton et al., 2010) and to manage the worry that the results of treatment were beyond their control (Beesley et al., 2013; Fitch & Steele, 2010; Steele & Fitch, 2008). Anxiety (Beesley et al., 2013; Steele & Fitch, 2008), feelings of sadness and depression (Beesley et al., 2013; Fitch & Steele, 2010; Steele & Fitch, 2008) and other emotional problems (Kornblith et al., 2010; Matulonis et al., 2008) were identified as

needs for women during survivorship. Women also experienced changes to their self-image and self-confidence as a result of their disease or the side effects of treatment such as lymphoedema (Beesley et al., 2007; Beesley et al., 2015; Olesen et al., 2015). Women also reported that they needed help to manage their own and other's expectations of them as a 'cancer survivor' (Hodgkinson et al., 2007; Rowlands et al., 2015).

Socially the impact of their cancer continued into the survivorship for women who participated in the studies include in this review. Women felt concerned about the worries of those close to them (Beesley et al., 2008; Beesley et al., 2013; Fitch & Steele, 2010; Steele & Fitch, 2008)and felt the need to protect and not upset their friends and family (Olesen et al., 2015). Some women felt that they needed help to cope with others not acknowledging the impact that cancer has had on their life (Hodgkinson et al., 2007; Rowlands et al., 2015) and felt that friends and family do not understand their concerns (Olesen et al., 2015). Several studies reported that women needed to share their experiences with other women who had survived cancer, particularly the same cancer as them (Beesley et al., 2007; Philp et al., 2017; Urbaniec et al., 2011). Dealing with the overall impact of their cancer on family and friends was a need identified by women in studies by Beaver and Booth (2007), Kornblith et al. (2010) and Matulonis et al. (2008).

The psychosexual needs of survivors of gynaecological cancer were investigated in some studies of the studies included in this review (Kornblith et al., 2010; Matulonis et al., 2008; Olesen et al., 2015; Philp et al., 2017; Rowlands et al., 2015; Walton et al., 2010). A fear of intercourse, uncertainty about resuming intercourse, loss of sexual desire and an overall impact on relationships, intimacy and sex life were identified as psychosexual needs for survivors of gynaecological cancer.

Needs of women with recurrent disease

Three of the 25 studies included in this review researched women who had recurrent disease (Jolicoeur, O'Connor, Hopkins, & Graham, 2009; Papadakos et al., 2012; Walton et al., 2010). Only the study by Jolicoeur et al. (2009) exclusively considered women in this phase of their disease and the results of this study are included in Table 4. As these women are often faced with new decisions regarding treatment, informational and practical needs surrounding this were important.

Jolicoeur et al. (2009) found that women making decisions in regard to treatment for recurrent ovarian cancer wanted to be presented with more than one treatment option which was supported by the study by Papadakos et al. (2012). Women also specified that they wanted counselling from nurses in regard to their treatment options as they perceived that the nurses had more time to spend with them, knew them better and had better skills in providing the information (Jolicoeur et al., 2009). Participants in the study by Walton et al. (2010) stated that they wanted information to be tailored to their situation, provided at appropriate times, and supported by written information that could be taken home after consultations. As new decisions were being made, women required information about the symptoms of the disease ongoing and each of the treatment options and the management and prevention of associated side-effects (Papadakos et al., 2012).

On a practical level, women who participated in the included studies desired a holistic approach to care with a central point of contact, including formal assessment and referral for services that continued even after treatment stopped (Walton et al., 2010). The women in the study by Walton et al. (2010) wanted a preparatory session before the commencement of treatment and wished to be involved in treatment decisions. This was supported by some women in the study by Jolicoeur et al. (2009) though others in that study were satisfied with playing a passive role in decision making regarding treatment of recurrence.

Women with recurrent disease identified that they needed help with physical symptoms and side-effects including management of bowel issues, pain and tiredness (Papadakos et al., 2012; Walton et al., 2010). Additionally, participants in the study by Papadakos et al. (2012) required assistance to manage nausea and vomiting, whilst participants in the study by Walton et al. (2010) also needed help with urinary and vaginal changes and menopausal symptoms. As for the earlier phases of disease, fear of recurrence remained an unmet need and women in this phase sought reassurance and validation from health professionals for the confusion, fear and other stressors related to their cancer experience (Walton et al., 2010).

Palliative care needs of women with gynaecological cancer

Only one study specifically investigated the palliative care needs of women with gynaecological cancer (Seven, Sahin, Yilmaz, & Akyuz, 2016). Women in this study were a mean of 24 months post-diagnosis and mainly reported having physical unmet needs including: pain, shortness of breath, nausea, lack of appetite, tiredness and problems carrying out physical activities (Seven et al., 2016). Psychologically the women in the study by Seven et al. (2016) reported feeling depressed and worried and had not received help for this.

Just one study included in this review did not report on the phase of disease for its participants at the time the research was conducted (Baldwin & Usher, 2008). The study by Baldwin and Usher (2008) considered the experiences of women living in rural and remote parts of Northern Australia. The women in this study had difficulty having their informational needs met given they lived so far away from their health services and relied heavily on the internet to fill this void. As for women in other studies (Beesley et al., 2007; Philp et al., 2017; Urbaniec et al., 2011), they wished to have contact with other women who had experienced similar cancers(Baldwin & Usher, 2008).

Specific and common needs of women with each gynaecological cancer type

Capacity to identify the specific needs of women with each of the gynaecological cancer types is limited to the analysis of studies where only women with one cancer type were included or where women with different cancer types within the one study were analysed separately. Two studies did not report on the type of gynaecological cancer of their participants (Baldwin & Usher, 2008; Olesen et al., 2015). The findings presented in Table 4 are coded (in brackets) according to the gynaecological cancer type they relate to. Despite each of the gynaecological cancers having different treatment pathways and different morbidity and mortality rates, there were few distinct differences between the needs of women with each of the gynaecological cancer types, as identified in the studies included in this review.

Treatment focused genetic testing – Ovarian cancer

Gleeson et al. (2013) studied the information and communication needs of women with ovarian cancer in relation to treatment focused genetic testing (TFGT). TFGT aims to identify the presence of a BRCA mutation in ovarian cancer patients to determine an optimal treatment pathway (Gleeson et al., 2013). This study found that women needed to have information about TFGT before commencement of surgery or chemotherapy and wanted that information to be provided by a genetic specialist, medical oncologist or gynaecological oncology nurse (Gleeson et al., 2013).

Lower limb lymphoedema – Vulval, Endometrial and Cervical cancer

Although lower limb lymphoedema (LLL) may be experienced by women with any type of gynaecological cancer, Beesley et al. (2007) found that the prevalence of this side effect of surgical dissection of pelvic lymph nodes is considerably higher in women with vulval cancer. The only study

included in this review exclusively considering the needs of women with vulval cancer found that women with LLL reported needs with regard to the physical and practical impact of this side effect (Philp et al., 2017). The women in the study by Philp et al. (2017) reported needs relating to the financial costs of lymphoedema; pain and discomfort; clothing and undergarment issues. One study involving only women with endometrial cancer (Beesley et al., 2015) identified the lymphoedema-specific supportive care needs of this group. These needs included: the costs of managing lymphoedema; pain and discomfort in the legs or groin; the need to be informed about the causes, prevention and treatment of lymphoedema; information and assistance to manage the symptoms of lymphoedema; coping with the changes to self-image as a result of lymphoedema; managing lymphoedema in the workplace; and completing daily activities around the home with lymphoedema (Beesley et al., 2015). Another study involving cervical and endometrial cancer patients (Jeppesen et al., 2015) identified the management of LLL as a need for the participants. None of the seven studies included in this review exclusively researching ovarian cancer patients identified any needs relating to lymphoedema. Lymphoedema related needs were reported in the study by Beesley et al. (2007) where n=48 of the 234 women (29.2%, 6.0% of overall sample) with ovarian cancer included in the study were either diagnosed with lymphoedema or had undiagnosed lower limb swelling.

Other tumour-specific needs

Vulval cancer patients participating in the study by Philp et al. (2017) needed more information specific to their disease and also wanted to meet with other women with vulval cancer. Although this was a need of women with other gynaecological cancers, the relatively low incidence of vulval cancer compared with the other cancers made these needs more difficult for women to meet. Women with cervical cancer had a unique unmet informational need in relation to the transmission of the human papilloma virus (HPV) responsible for their cancer (Olesen et al., 2015).

Needs common to women with all gynaecological cancers

Regardless of their tumour type, women with gynaecological cancer needed help to manage their fears of their cancer recurring or spreading (Beesley et al., 2008; Beesley et al., 2013; Fitch & Steele, 2010; Hodgkinson et al., 2007; Papadakos et al., 2012; Ploegsma, 2016; Rowlands et al., 2015; Steele & Fitch, 2008; Urbaniec et al., 2011; Walton et al., 2010). This was the top ranked need or unmet need in six of the quantitative studies measuring needs (Beesley et al., 2008; Beesley et al., 2013; Fitch & Steele, 2010; Hodgkinson et al., 2007; Steele & Fitch, 2008; Urbaniec et al., 2011). Likewise, women with all types of gynaecological cancer experienced uncertainty about their future (Beesley et al., 2008; Beesley et al., 2013; Fitch & Steele, 2010; Jeppesen et al., 2015; Rowlands et al., 2015; Steele & Fitch, 2008; Walton et al., 2010) and needed help to manage this.

In regards to the care that they received, women with all types of gynaecological cancer wanted to receive holistic, patient-centred care (Beesley et al., 2013; McCallum et al., 2012; Olesen et al., 2015; Philp et al., 2017; Walton et al., 2010). Women also wanted a central contact within the healthcare system that they could speak to if they had any concerns (Beesley et al., 2013; Ploegsma, 2016; Urbaniec et al., 2011; Walton et al., 2010) and needed to be reassured that their doctors were talking to each other to coordinate their care (Hodgkinson et al., 2007; Ploegsma, 2016; Rowlands et al., 2015; Urbaniec et al., 2011). Further practical needs were identified across the gynaecological cancers including a need for complaints about care to be addressed satisfactorily (Hodgkinson et al., 2007; Ploegsma, 2016; Rowlands et al., 2015), access to complimentary and alternative therapies (Hodgkinson et al., 2007; Ploegsma, 2016; Rowlands et al., 2015; Walton et al., 2010) and local health services to be available when needed (Hodgkinson et al., 2007; Ploegsma, 2016; Rowlands et al., 2015).

Across all gynaecological cancers, women wanted information that was specific to their cancer, was delivered in a form that they could understand, and was supported by written material that could be

referred to later if needed (Beesley et al., 2015; Gleeson et al., 2013; Hodgkinson et al., 2007; Philp et al., 2017; Ploegsma, 2016; Walton et al., 2010). Psychosexual needs were identified in studies including women with all gynaecological cancer types (Kornblith et al., 2010; Matulonis et al., 2008; Olesen et al., 2015; Philp et al., 2017; Rowlands et al., 2015; Walton et al., 2010).

Tools used to measure needs in women with gynaecological cancer

The 16 quantitative studies included in this review utilised seven different tools to measure needs or unmet needs in women with gynaecological cancer. Table 5 presents the seven different tools, a brief explanation of the measure and a list of the studies which utilised each tool. With the exception of the study by Papadakos et al. (2012) which utilised a non-validated questionnaire to identify informational needs, all other quantitative studies utilised validated and reliable tools to measure needs. Although some studies measured need with the same tools, their samples were heterogenous and thus not possible to conduct a meta-analysis.

[Insert Table 5]

Discussion

This review has integrated both qualitative and quantitative studies relating to the needs of women with gynaecological cancer in developing nations, who have access to treatment. The needs of women with gynaecological cancer were reviewed across the trajectory of their disease and many needs identified were common to all gynaecological cancer types with only a few needs specific to given cancer types. The 25 studies included in this review provided a comprehensive overview of the needs of women with gynaecological cancer who had access to treatment of their disease. The proportions of participants with each cancer type included in this review is reflective of incidence rates and burden of these cancers in developed nations compared with developing nations where cervical cancer is more prevalent.

Identifying the different needs of women across their disease trajectory allows for targeted care and intervention at specific phases of the woman's cancer journey. More than half of the studies in this review included women during the survivorship phase of their disease which has highlighted the needs, many unmet, of survivors of gynaecological cancer that continue when treatment has ceased. At this point women resume 'normal' life and cease frequent contact with the health care team, moving into follow-up care. Fear of cancer recurrence or spread were the top ranked need or unmet need for survivors of gynaecological cancer in six studies and were identified as a high priority need in four others in this review. These results are corroborated by the findings of recent systematic reviews considering the prevalence, correlates and management of fear of recurrence in different cancer populations (Cancer Australia, 2013b; Crist & Grunfeld, 2013; Simonelli, Siegel, & Duffy, 2017). Fear of cancer recurrence is prevalent among adult cancer survivors and has been found to have a relationship with younger age (Crist & Grunfeld, 2013); coping responses (Crist & Grunfeld, 2013); poorer quality of life (Cancer Australia, 2013b; Crist & Grunfeld, 2013); cues such as new symptoms, pain and follow-up appointments (Crist & Grunfeld, 2013); more side effects of treatment (Cancer Australia, 2013b) and psychological outcomes (Cancer Australia, 2013b). Only one of the studies in this review specifically investigated the correlates of fear of cancer recurrence and found that emotional wellbeing was a strong predictor of fear of cancer recurrence in gynaecological cancer survivors (Urbaniec et al., 2011). The prevalence of fear of recurrence in this population warrants further research into the predictors and interventions to manage this need. Management of fear of cancer recurrence remains under-researched though some psychological therapies were identified as useful in the reviews and guidelines by Cancer Australia (2013b, 2014); Crist and Grunfeld (2013); Simonelli et al. (2017)

Understanding the needs specific to each phase of the disease and to each gynaecological cancer type allows health care professionals to provide appropriate and timely support. Studies in this review utilised tools to determine the needs of a sample of women with a gynaecological cancer at one or two points in time. However none of the studies evaluated the use of a needs screening tool on a regular basis as a means of providing patient-centred, holistic care as desired by women participating in studies included in this review (Beesley et al., 2013; McCallum et al., 2012; Olesen et al., 2015; Philp et al., 2017; Walton et al., 2010). A systematic review by Cook et al. (2017) determined that women valued the care provided by specialist gynaecological oncology nurses because it was tailored to their needs based on regular, formal assessment. The review also found that specialist nurses provided women with gynaecological cancer a central point of contact and were often responsible for the coordination of their care (Cook et al., 2017) which were needs identified in the current review. Gynaecological oncology specialist nurses are well placed to assist women to meet these and other needs identified through this review. Further studies should consider the use of needs assessment tools on a regular basis and the development of pathways for specialist nurses or other health professionals to follow when needs arise for these women.

Limitations of review

The significant and growing burden of cervical cancer in developing nations requires that further research be conducted into the needs of women who may have limited or no access to the treatment of their gynaecological cancer. A further limitation of this review relates to the analysis and reporting of highest ranked needs only. The prevalence, intensity or ranking of the needs as reported in the original study was not analysed. The different tools utilised by studies to measure needs prohibited the comparison of needs at that level.

Several studies included in this review considered the correlates of needs in women with gynaecological cancer (Beesley et al., 2008; Beesley et al., 2007; Beesley et al., 2013; Beesley et al., 2015; Hodgkinson et al., 2007; Rowlands et al., 2015; Urbaniec et al., 2011) though these were not analysed in this review. These papers found varying relationships between needs and psychological measures, quality of life, demographic characteristics, diagnosis and treatment variables, coping, optimism/pessimism, relationship adjustment, physiological conditions, heath behaviours, social support and community factors. Further analysis of the potential risk factors for needs and unmet needs in women with gynaecological cancer is recommended in order to provide valuable information to health professionals in identifying and addressing needs in this population.

Conclusion

This review has integrated the results of quantitative and qualitative research on the needs of women with gynaecological cancer across their disease trajectory. Informational needs were prominent around the phases of diagnosis, treatment and recurrence of disease, with women wanting information about their disease, the treatments and the side effects of treatment. Psychological needs such as management of fear of recurrence and feelings of uncertainty first arise at the time of diagnosis but persist into the survivorship period for women with gynaecological cancer. Although no longer receiving treatment for their disease, practical needs relating to their cancer such as the need for holistic, coordinated care and access to local health services were reported by gynaecological cancer survivors. Most of the needs identified through this review were common to women with all types of gynaecological cancer though some needs, such as those relating to lower limb lymphoedema and genetic testing, were more relevant to women with particular cancer types.

Relevance to clinical practice

The identification of needs and unmet needs is integral to the provision of holistic, individualised care to women with gynaecological cancer. This review has identified the needs of women with gynaecological cancer along their disease trajectory which may be used by clinicians as a guide to provide targeted and timely care. Further research is necessary to investigate the effectiveness of regular needs assessment for women with gynaecological cancer, particularly in survivorship when contact with the health care team becomes less frequent, as a guide for the provision of holistic and patient-centred care. Whilst this review has highlighted the prominent needs of women with gynaecological cancer, interventional studies testing strategies to manage needs identified through regular, formal assessment are suggested.

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Table 1 Characteristics of included studies

Quantitative Studies n= 16

Study Design			Participant characteristics				Appraisal
Study	**Purpose and Setting**	**Methods**	**Sample size**	**Time since diagnosis (years)**	**Tumour type†**	**Phase****	**Quality rating§**
Beaver & Booth (2007)	*Purpose*: To examine the information needs and treatment decision-making preferences of women treated for gynaecological cancers *Setting*: Specialist gynaecological oncology service *Country*: UK	*Design*: Survey *Sampling*: Convenience *Data collection: Structured interviews* *Time points*: Single	N = 53	Mean 0.31	Cervix n=21 Ovary n=5 Uterus n=21 Vulva n=5 Vagina n=1	T-S	M
Beesley, Eakin, Steginga et al (2008)	*Purpose:* To determine the prevalence of unmet support needs, and to evaluate the correlates associated with higher levels of unmet need across multiple need domains *Setting:* Queensland gynaecological cancer registry & treating hopsitals *Country*: Australia	*Design*: Cross-sectional *Sampling*: Random sample from cancer type and survival phase strata of population-based state registry of gynaecological cancers *Data collection:* Mailed survey *Time points*: Single	N = 802	0.25-1.0 years n=190, 23.7% 1–3 years n=335, 41.8% 4–5 years n=277, 34.5%	Cervix n=197 Ovary n=234 Uterus n =243 Other n=128	S	H

Study Design			Participant characteristics				Appraisal
Study	**Purpose and Setting**	**Methods**	**Sample size**	**Time since diagnosis (years)**	**Tumour type†**	**Phase‡**	**Quality rating§**
Beeley, Janda, Eakin, Obermair & Battitutta (2007)	*Purpose:* To establish prevalence, correlates and supportive care needs of gynaecological cancer survivors who develop lymphoedema *Setting*: Queensland gynaecological cancer registry & treating hopsitals *Country*: Australia	*Design*: Cross-sectional *Sampling*: Random sample from cancer type and survival phase strata of population-based state registry of gynaecological cancers *Data collection:* Mailed survey *Time points*: Single	N = 802	0.25-1.0 years n=190, 23.7% 1–3 years n=335, 41.8% 4–5 years n=277, 34.5%	Cervix n=197 Ovary n=234 Uterus n=243 Vulva n=53 Other n=75	S	H
Beesley, Price & Webb et al (2013)	*Purpose:* To determine changes in supportive care needs after first-line treatment for ovarian cancer and identify risk factors for future unmet needs. *Setting*: Australian Ovarian Cancer Study *Country*: Australia	*Design*: Longitudinal population-based survey *Sampling*: QoL sub-sample of Australian Ovarian Cancer Study *Data collection:* Mailed survey *Time points*: 6-monthly intervals for 2 years. Baseline at 6-12 months post-diagnosis	N =219	0.5-1.0 year at baseline	Ovarian	S	H
Beesley, Rowlands & Hayes et al (2015)	*Purpose:* To quantify cumulative incidence of, and risk factors for developing lymphoedema following treatment for endometrial cancer and estimate absolute risk for individuals and report on unmet needs for help with lymphoedema-specific issues. *Setting*: Australian National Endometrial Cancer Study (ANECS) *Country*: Australia	*Design*: Population-based case control study *Sampling*: Sub-sample from ANECS cohort *Data collection:* Self-administered questionnaire *Time points*: Single	N = 643	3-5 years	Endometrial	S	H

Study Design			Participant characteristics				Appraisal
Study	**Purpose and Setting**	**Methods**	**Sample size**	**Time since diagnosis (years)**	**Tumour type†**	**Phase‡**	**Quality rating§**
Fitch & Steele (2010)	*Purpose:* To identify the supportive care needs of women with ovarian cancer and to determine if women wanted assistance in meeting those needs. *Setting:* Comprehensive ambulatory cancer centre *Country*: Canada	*Design*: Cross-sectional, descriptive *Sampling*: Consecutive *Data collection:* Self-report questionnaire *Time points* :Single	N = 50	<1 year n= 28 1-2 years n=8 >2 years n=14	Ovarian	T-S	H
Hodgkinson, Butow & Fuchs et al (2007)	*Purpose:* To assess the long-term psychosocial outcomes and supportive care needs of gynaecologic caner survivors *Setting:* Gynaecologic cancer centre *Country*: Australia	*Design*: Descriptive *Sampling*: Sub-samples from two larger studies *Data collection: Self-report questionnaires* *Time points*: Single	N = 199	Mean 3.7 years Range 1-8 years	Cervix n=40 Ovary n =54 Uterus n=91 Vulva/Vagina n=14	S	H
Jeppesen, Mogensen, Dehn & Jensen (2015)	*Purpose* To identify short-term rehabilitation needs of women with endometrial and cervical cancer *Setting*: Tertiary hospital *Country*: Denmark	*Design*: Exploratory *Sampling*: Convenience *Data collection:* Self-report questionnaire *Time points*: Two – post-diagnosis but pre-commencement of treatment and 3 months later	N = 96	At diagnosis for baseline	Cervical n=44 Endometrial n=52	D-T	H
Kornblith, Mirabeau-Beale & Lee et al (2010)	*Purpose:* To describe the long-term adjustment of ovarian cancer survivors diagnosed with advanced disease. *Setting:* Three centres treating women with gynaecological cancer in Massechusetts. *Country*: US	*Design*: Descriptive *Sampling*: Convenience, eligibility confirmed by treating doctor *Data collection:* Structured interviews – in-person or telephone *Time points*: Single	N = 42	Mean 6.1 years	Ovarian	S	M

Study Design			Participant characteristics				Appraisal
Study	**Purpose and Setting**	**Methods**	**Sample size**	**Time since diagnosis (years)**	**Tumour type†**	**Phase‡**	**Quality rating§**
Matulonis, Kornblith & Lee et al (2008)	*Purpose:* To describe the quality of life, consequences of treatment, complementary therapy use and factors correlating with psychologic state in early-stage ovarian cancer survivors. *Setting:* Three centres treating women with gynaecological cancer in Massechusetts *Country*: US	*Design*: Cross-sectional *Sampling*: Convenience, eligibility confirmed by treating doctor *Data collection: Self-report questionnaires either mailed or provided at clinic* *Time points*: Single	N = 58	Mean 5.8 years Range 3-15 years	Ovarian	S	M
Papadakos, Bussiere-Cote & Abdelmutti et al (2012)	*Purpose:* To identify the informational needs of gynaecologic caner patients and to inform the development of resources and programs for gynaecologic patients *Setting*: Gyanecologic oncology clinic at one hospital *Country*: Canada	*Design*: Cross-sectional, observational *Sampling*: Convenience sample of clinic patients *Data collection:* Non-validated self-administered questionnaire distributed at clinic *Time points*:Single	N = 185	At diagnosis n=68, 37.8% Long-term Follow-up n=48, 26.7% Recurrent disease n=64, 35.6%	Cervix n=23 Ovary n=91 Uterus/Endo metrial n=43 Vulva/Vaginal /GTD n=10 >2 primary sites n=18	D-S-R	M
Phloegsma (2016)	*Purpose:* To examine the relationship between supportive care needs and health-related quality of life in Dutch ovarian cancer survivors. *Setting*: Eindhoven Cancer Registry *Country*: Denmark	*Design*: Cross-sectional *Sampling*: Sub-sample of cross-sectional population-based study *Data collection: Mailed or online self-administered questionnaires* *Time points*: Single	N = 266	Mean 6.28 years	Ovarian	S	H

Study Design			Participant characteristics				Appraisal
Study	**Purpose and Setting**	**Methods**	**Sample size**	**Time since diagnosis (years)**	**Tumour type†**	**Phase‡**	**Quality rating§**
Rowlands, Janda, McKinnon, Webb & Beesley (2015)	*Purpose:* To examine prevalence, sociodemographic and clinical predictors, and physical and psychosocial correlates of unmet needs among endometrial cancer survivors. *Setting*: Australian National Endometrial Cancer Study (ANECS) *Country*: Australia	*Design*: Population-based case-control study *Sampling*: Sub-sample from ANECS cohort *Data collection: Mailed self-administered questionnaire* *Time points:*Two - at diagnosis and 3-5 years later	N = 629	At diagnosis for baseline Time 2: Mean 4.1 years (range 2.9-6.3 years)	Endometrial	S	H
Seven, Sahin, Yilmaz & Akyuz (2016)	*Purpose:* To identify gynaecologic cancer patients' palliative care needs *Setting*: Training and research hospital in Ankara *Country*: Turkey	*Design*: Cross-sectional descriptive *Sampling*: Convenience *Data collection: Self-report survey* *Time points*: Single	N = 134	Mean 2.02 years Range (0.16-8 years)	Cervix n=4 Ovary n=93 Endometrium n=35 Vulva n=2	T-P	M
Steele & Fitch (2008)	*Purpose:* To identify the supportive care needs of women with gynaecologic cancer and if patients wanted assistance with those needs *Setting*: Comprehensive outpatient cancer centre in Ontario *Country*: Canada	*Design*: Cross-sectional descriptive *Sampling*: Convenience *Data collection: Self-report questionnaire* *Time points*: Single	N = 103	<1 year n=29 1-2 years n=38 >2 years n=34	Cervix n=21 Ovary n=50 Uterus/Endometrium n=8 Vulva n=19 Other n=4	T-S	H
Urbaniec, Collins, Denson & Whitford (2011)	*Purpose:* To identify the supportive care needs gynaecological cancer survivors *Setting*: One cancer centre in Adelaide *Country*: Australia	*Design*: Cross-sectional *Sampling*: Convenience *Data collection: Self-report questionnaire* *Time points*: Single	N = 45	Mean 4.0 years (Range 0.9-11.6 years)	Cervix n=12 Ovary n=12 Uterus/Vulva/vaginal n=10 Endometrium n=9 Multiple n=2	S	H

Qualitative Studies n= 9

Study Design			Participant characteristics				Appraisal
Study	**Purpose and Setting**	**Methods**	**Sample size**	**Time since diagnosis (years)**	**Tumour type†**	**Phase‡**	**Quality rating§**
Baldwin & Usher (2008)	*Purpose: To obtain an undersanding of the experience of women who live with gynaecological cancer and who reside in rural and remote areas of North Queensland* *Setting*: Rural and remote areas of North Queensland *Country*: Australia	*Design*: Phenomenological *Sampling*: Purposive *Data collection:* In-depth one-on-one interviews *Time points*: Single	N=7	NR	All – Not specified	NR	H
Gleeson, Meiser & Barlow-Stewart et al (2013)	*Purpose:* To identify women's information and communication preferences about treatment-focused genetic testing (TFGT) in the ovarian cancer context *Setting*: Two familial canccer services and a gynaecologic oncology clinic at a major teaching hospital *Country*: Australia	*Design*: Qualitative *Sampling*: Purposive *Data collection:* Semi-structure one-on-one interviews *Time points*: Single	N = 22	Group A 1-14 years Group H 0.12-0.38 years	Ovarian	Group A – S Group H-T	H
Holt, Hansen & Mogensen (2014)	*Purpose:* To investigate the need for supportive care among women with gynaecological cancer and their relatives during the diagnostic period *Setting*: Tertiary hospital *Country*: Denmark	*Design*: Qualitative descriptive *Sampling*: Convenience, purposive *Data collection:* Semi-structured interview *Time points*: Pre or post initial out-patient clinic appointment	N = 16	Pre-diagnosis	Cervix n=1 Ovary n= 10 Uterus n= 3 Vulva n=2	D	H

Study Design			Participant characteristics				Appraisal
Study	**Purpose and Setting**	**Methods**	**Sample size**	**Time since diagnosis (years)**	**Tumour type†**	**Phase‡**	**Quality rating§**
Jolicoeur, O'Connor, Hopkins & Graham (2009)	*Purpose:* To describe the decision-making needs of women with ovarian cancer related to treatment of recurrent disease. *Setting:* One cancer centre *Country:*Canada	*Design*: retrospective, cross-sectional *Sampling*: Convenience *Data collection:* Semi-structured face-to-face interview *Time points*: Single	N = 13	NR	Ovarian	R	H
Long, Friedrich-Nel & Joubert (2016)	*Purpose:* To identify the information needs of South African women receiving intracavity brachytherapy for locally advanced cervical cancer. *Setting:* Brachytherapy unit, tertiary hospital *Country*: South Africa	*Design*: Prospective phenomenological study *Sampling*: Purposive *Data collection:* Semi-structured face-to-face interviews *Time points*: Single	N = 28	NR	Cervical	T	H
McCallum, Lefebvre, Jolicouer, Maheu & Lebel (2012)	*Purpose:* To explore the subjective experiences of women treated for a gynaecological cancer including services desired to meet needs. *Setting:* Regional cancer centre *Country:*Canada	*Design*: Interpretive description *Sampling*: Purposive *Data collection:* Semi-structured face-to-face interviews *Time points*: Single	N = 15	NR	Cervix n=3 Ovary n=3 Uteru/Endometrium n= 5 Vulva/Vagina n=5	S	H
Olesen, Hansson & Ottensen et al (2015)	*Purpose:* To explore gynaecological cancer survivors' need for rehabilitation during follow-up and to develop an appropriate intervention targeted at these needs. *Setting:* Outpatient clinic of tertiary hospital *Country:*Denmark	*Design*: Qualitative interviews *Sampling*: Purposive *Data collection:* Semi-structured face-to-face interviews *Time points*: Single	N = 6	1-5 years	All – not specified	S	M

Study Design			Participant characteristics				Appraisal
Study	**Purpose and Setting**	**Methods**	**Sample size**	**Time since diagnosis (years)**	**Tumour type†**	**Phase‡**	**Quality rating§**
Philp, Mellon, Barnett, D'Abrew & White (2017)	*Purpose:* To explore and describe women's experiences of diagnosis, treatment for and recovery from vulval cancer. *Setting:* Two gynaecoloigical cancer services – one regional, one metropolitan. *Country*: Australia	*Design*: Qualitative interviews *Sampling*: Convenience *Data collection:* Semi-structured face-to-face or telephone interviews *Time points*: Single	N = 12	Up to 5 years	Vulval	S	M
Walton, Reeve, Brown & Farquhar (2010)	*Purpose: To identify women's needs for supportive care and to understand to what extent they feel those needs are being met by health services.* *Setting:* Gynaecology service in a tertiary hospital *Country:* New Zealand	*Design*: Qualitative interviews *Sampling*: Purposive *Data collection:* Unstructured face-to-face interviews. *Time points*: Single	N = 28	<1 year n = 9 1-2 years n=11 3-5 years n= 8	Cervix n=7 Ovary n=10 Endometrium n= 9 Vulva n=2	T-S-R	M

†Where 'All' is denoted this refers to all gynaecological tumour types

‡ (D) – Pre-diagnosis/ Diagnosis; (T) – Treatment phase; (S) Survivorship; (R) Disease recurrence; (NR) Not reported

§ (M) Moderate quality; (H) High quality

Table 2 Definition of terms used in this integrative review

Term	Definition
Pre-diagnosis/Diagnosis	The phase when a gynaecological cancer is suspected or has been diagnosed. A definitive diagnosis is not known until surgical staging has occurred.
Treatment	The phase during which women receive surgery and/or chemotherapy and/or radiotherapy for their cancer.
Survivorship	The phase of disease where patients are not requiring treatment for their cancer and attend regular follow-up visits aimed at monitoring for recurrence of disease.
Recurrence	The phase when a recurrence of disease has occurred since first-line treatment and further treatment is required.
Palliative / End of life	The phase when women receive supportive care for a life-threatening disease
Needs	Problems or priorities of women with gynaecological cancer for which they require or have required attendance.
Unmet needs	Problems or priorities of women with gynaecological cancer for which the woman has not been able to attend or get help with.
Information needs	Needs relating to information about any aspect of the disease, its treatment or symptoms and side effects required by women
Physical needs	Needs relating to the symptoms of disease and side effects of treatment and performing usual physical activities and tasks.
Psychological/Emotional needs	Needs relating to the psychological and emotional effects of having cancer and the management of these.
Practical needs	Needs relating to accessing treatment, navigation of services and management of daily life with cancer.
Psychosexual needs	Needs relating to sexual relationships and women's sexuality with regard to their cancer
Social needs	Needs relating to how women with gynaecological cancer function within their family and friendship groups, communities and society as a whole.

Table 3: Studies including women at given phases on the disease trajectory†

Disease phase	n	Studies including participants at given phase of disease
Pre-diagnosis/Diagnosis	3	**Jeppesen, Mogensen, Dehn & Jensen (2015)**; Papadakos, Bussiere-Cote & Abdelmutti et al (2012); **Holt, Hansen & Mogensen (2014)**
Treatment	6	Beaver & Booth (2007); Fitch & Steele (2010); **Jeppesen, Mogensen, Dehn & Jensen (2015;** Steele & Fitch (2008); **Long, Friedrich-Nel & Joubert (2016)**; **Gleeson, Meiser & Barlow-Stewart et al (2013)**
Survivorship	19	Beaver & Booth (2007); **Beesley, Eakin, Steginga et al (2008); Beesley, Janda, Eakin, Obermair & Battitutta (2007)**; **Beesley, Price & Webb et al (2013)**; **Beesley, Rowlands & Hayes et al (2015)**; Fitch & Steele (2010); **Hodgkinson, Butow & Fuchs et al (2007)** ; **Kornblith, Mirabeau-Beale & Lee et al (2010) ; Matulonis, Kornblith & Lee et al (2008)**; Papadakos, Bussiere-Cote & Abdelmutti et al (2012); **Phloegsma (2016)**; **Rowlands, Janda, McKinnon, Webb & Beesley (2015)**; Steele & Fitch (2008); **Urbaniec, Collins, Denson & Whitford (2011)**; **Gleeson, Meiser & Barlow-Stewart et al (2013)**; **McCallum, Lefebvre, Jolicouer, Maheu & Lebel (2012)**; **Olesen, Hansson & Ottensen et al (2015); Philp, Mellon, Barnett, D'Abrew & White (2017)**; Walton, Reeve, Brown & Farquhar (2010)
Recurrence	3	Papadakos, Bussiere-Cote & Abdelmutti et al (2012); **Jolicoeur, O'Connor, Hopkins & Graham (2009)**; Walton, Reeve, Brown & Farquhar (2010)
Palliative care	1	Seven, Sahin, Yilmaz & Akyuz (2016)
Not reported	1	Baldwin & Usher (2008)

†Studies listed in **bold** include women in that phase only or discreet data for that phase

Table 4: Categorised needs identified by women at specific phases of gynaecological cancer

Phase of disease	Information needs	Psychological/ Emotional needs	Physical needs	Social needs	Practical needs	Psychosexual needs
Pre-diagnosis/ Diagnosis	-Overview of the pre-diagnostic /diagnostic period (All) -What they can do to prepare for surgery -Enough information to be able to ask the 'right' questions at the initial consultation. (All)	-Management of psychological aspects of diagnosis eg fear, anxiety, worry, and insomnia. (All, C, E)	-Management of fatigue† (C) -Management of bleeding/ discharge† (E)	-Deciding whether to involve family or friends at that stage (All)	-To focus on getting well† (C,E) -Practical aspects of treatment†: transportation (C, E); financial (C); child care (C); return to work (E).	
Treatment	-Information in patients own language (C) -opportunity to ask questions to ensure that consent is informed (C) -Treatment related (brachytherapy) including explanation of procedure, overview of treatment plan, side effects and resumption of sexual activity. (C) -How to prepare self for treatment (C) -Printed information in own language (C) - Information about treatment –focused genetic testing (TFGT)	-Worry about a cure† (C) - Management of psychological aspects of treatment† (C)	-Urological problems† (C,E) -Fatigue† (C, E) -Lymphoedema† (C,E) -Menopausal symptoms† (E) - Feeling of weight in abdomen† (E)	-Restrictions in practice of leisure activities† (E)	-To be informed of treatment schedule(C)	-Problems with sex life† (C)

	prior to surgery (O) - Information about TFGT to be delivered by a medical oncologist or their gynaecological oncology nurse face-to-face with brief supporting written information (O)					
Survivorship	-Symptoms of recurrence and spread of disease † (All) -Effects of treatment on fertility† (All) -fertility preservation prior to treatment† (All) -Up-to-date information (All, O) -information provided in a way that they can understand (All) -The causes, prevention and treatment of lymphoedema (All, E) -Provision of written information about management of lymphoedema (All, E) -Transmission of HPV† (C) -Information about treatment –focused genetic testing (TFGT)	-Guilt related to getting cancer† (All) -Lack of self-confidence† (All) -Sense of being out of control† (All) -Anger† (All) - Loneliness/ Isolation† (All) -Fear of cancer recurrence† (All, E, O) -Fear about cancer spreading† (All, O) -Uncertainty about future† (All, O) -Changes to belief that nothing bad will ever happen in their life† (All) -Help to reduce stress in life† (All, E) -Help to deal with their own or others' expectations of them as a cancer survivor† (All, E)	-Not being able to do the things they used to† (All) -Lack of energy† (All, O) -Pain or discomfort in legs due to lymphoedema† (All, E, V) -Help managing the symptoms of lymphoedema† (All, E, V) -management of ongoing side-effects and complications of treatment (E, O) -Management of hot flushes (E) -cancer-related physical needs (O) -Altered urinary function (V) -Clothing and undergarment issues (V)	-Friends and family do not understand concerns† (All) -Need to protect friends and family, not upset them (All) -Need to talk to others who have experienced cancer† (All) -Concerns about worries of those close to them† (All, O) -Help to cope with others not acknowledging the impact that cancer has had on their life† (All, E) -Finding a support group that addresses lymphoedema needs† (All) -Dealing with their partner's reaction to their lymphoedema†	-Holistic approach to care† (All, O, V) -Formal assessment and referral† (All) - A central contact/ case manager within the health service† (All, O) -More time during consultations to address other concerns not just physical † (All) -Doctors talk to each other to coordinate care † (All, E, O) -To feel like they are managing their health with their medical team (All, E, O) -The best medical care (All, O) -Local health services available when needed† (All, E, O) -For complaints about	-Loss of sexual desire† (All) -Fear of intercourse† (All) -address problems with sex life† (E,O) -Impact on relationships and intimacy (V)

	prior to surgery or prior to chemo commencing (O) - Information about TFGT to be delivered by a genectic specialist or medical oncologist face-to-face with brief supporting written information (O) -Medical information† (O) -Things they can do to help themselves get well† (O) -Being informed that the cancer is under control or diminishing† (O) -Information to be provided in a form they can understand -Up to date information (O) -Information for family and partners relevant to them (O) -Vulval cancer-specific printed information† (V)	-Help to adjust to changes to how they feel about their body† (All) -Help to make decisions about their life in the context of uncertainty† (All, E) -Coping with changes in self-image as a result of lymphoedema† (All, E) -Coping with the emotional shock of lymphoedema† (All) -Emotional support (E, O) -Spiritual needs (O) -Feelings of sadness (O) -Worry that the results of treatment are beyond their control† (O) -Feeling depressed or down (O) -Anxiety† (O) -Keeping a positive outlook† (O)	(All) - family problems† (O) -social support from friends† (O) - Restrictions in practice of leisure activities† (O) - Support group for women with vulval cancer (V)	care to be addressed (All, E, O) -More accessible hospital parking† (All, E) -Access to complimentary/ alternative therapy services† (All, E, O) -cost of having lymphoedema † (All, E, V) -Managing the symptoms of lymphoedema in the workplace† (All, E) -completing daily activities around house with lymphoedema † (All, E) -Medical insurance problems† (O) -Financial responsibilities (O) -Employment problems (O) -Transportation (O) -Medical staff (O) -childcare needs (O) -Being informed of test results as soon as feasible† (O)
Disease Recurrence	-To be presented with more than one			

	treatment option (O) -Counselling from nurses regarding treatment options (O)			
Palliative		-Depression† (All) -Worry† (All)	Pain† (All) -Shortness of breath† (All) -Nausea† (All) -Lack of appetite† (All) -Tiredness† (All) - Problems carrying out physical activities† (All)	
Phase not reported	-Understanding rationale for treatment plan (All) -Difficulty accessing information when so far from health service (All) -Reliance on internet for information (All)			-how other women have experienced similar cancers (All)

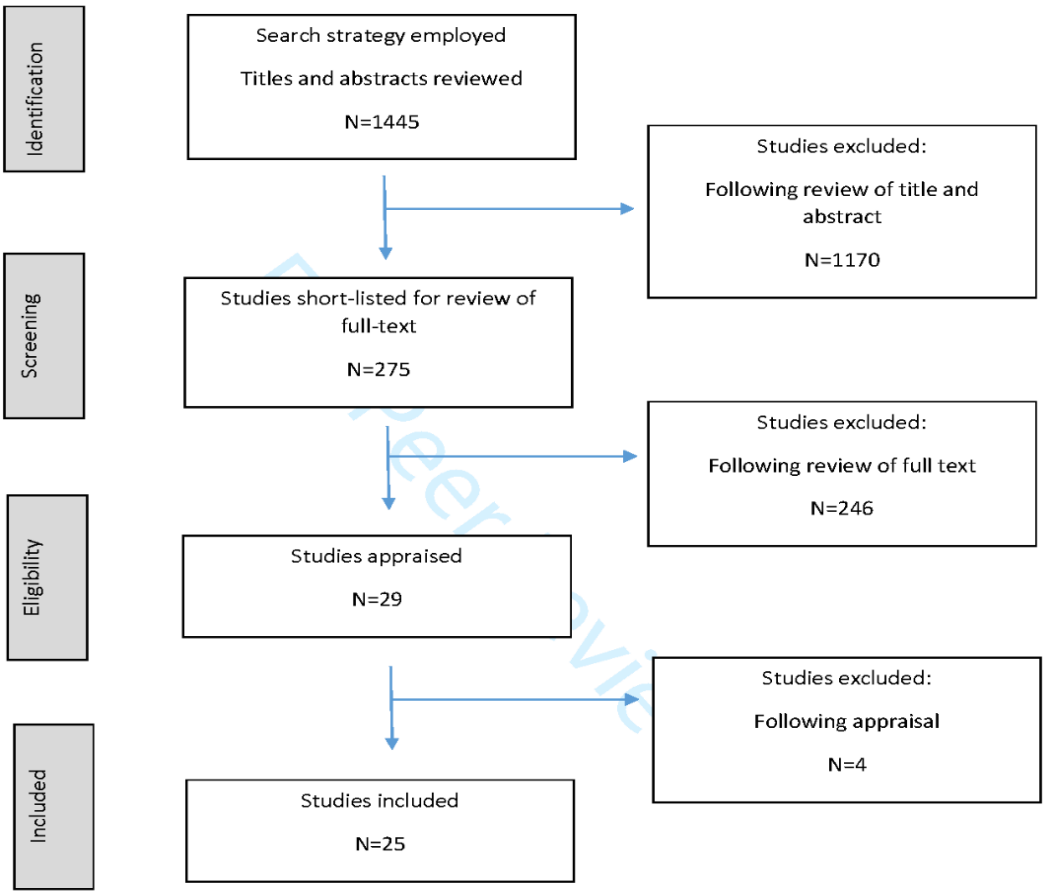
Findings from women with a particular cancer type only: (C) – cervical cancer; (O) – ovarian cancer; (E) – endometrial cancer; vulval cancer; (All) - All gynaecological cancers.

† – indicates where needs have been identified as unmet in a study

Table 5: Needs measurements utilised by quantitative studies

Needs measure (number of studies)	Brief description	Studies
Supportive care needs survey (SCNS) (5)	Self-administered questionnaire. Participants rank their level of need for each item on a 5-point scale ranging from no need to high need. 34 items are arranged under five needs domains.	Beesley et al 2008 Beesley et al 2007 Beesley et al 2013 Fitch & Steele, 2010 Steele & Fitch, 2008
Cancer survivors unmet needs measure (CaSUN) (4)	Self-administered questionnaire. 35 supportive care needs items under 5 domains, 6 positive outcome items and an open-ended item. Participants rank their needs in the past month on a scale of 0-4 with 0 being no need and 4 a strong unmet need.	Hodgkinson et al 2007 Phloegsma 2016 Rowlands et al 2015 Urbaniec et al 2011
Information needs Questionnaire (INQ) (2)	Nine items of information presented in pairs relating to physical, psychological and social aspects of care and treatment. Participants state a preference for one item out of the pair.	Beaver & Booth 2007 Seven et al 2016
Unmet Needs (2)	14 items relating to possible unmet needs relevant to cancer patients. Participants rate items on a 3-point Likert scale ranging from 1 (got as much help as needed) to 3 (much less help than needed)	Kornblith et al 2010 Matulonis et al 2008
Three level of needs questionnaire (3LNQ) (1)	Assesses 12 needs using three parallel approaches: 'Problem intensity'; 'Problem burden; and 'Felt need'. This tool also contains a priority list where the participant lists their most urgent problems.	Jeppesen et al 2015
Lymphoedema-specific supportive care needs	A supplement to the CaSUN containing 11 support-need items for women with lymphoedema symptoms.	Beesley et al 2015 Beesley et al 2007
Non-validated/author created	3 major sections: Demographics and health information; informational needs; comments where participants were asked to elaborate on their current informational needs	Papadakos et al 2012

Figure 1 PRISMA flowchart of study selection and inclusion process (Moher, Liberati, Tetzlaff, Altman, & The Prisma Group, 2009)



Summary

The integrative review synthesised evidence on the needs of women with gynaecological cancers from developed nations. The findings of the systematic and integrative reviews were complimentary and together found that women with gynaecological cancers valued holistic and individualised care. Women also appreciated and needed a central point of contact - an easily accessed member of the treatment team who knew them well. Women with gynaecological cancers needed to know that their specialists were communicating to coordinate their care and required assistance to navigate their way through the healthcare system. The findings of the two reviews indicated that women valued having access to clinical expertise for the management of symptoms and side effects and a source of information delivered in a way that they could understand. Together the two reviews and the theoretical forestructure in Chapter 1 provide the 'scaffold' upon which this study was designed and implemented and offers the perspective of women with gynaecological cancers to this study. The variable methodological design and quality of the studies in these reviews do not allow conclusions to be drawn on the efficacy or benefit of specialist nursing care.

Chapter 4 - Methodology and Methods

Introduction

This chapter details the methodology and methods utilised in this study. This qualitative study employed an Interpretive Description methodology based on its aim to generate knowledge for nursing practice. A detailed description of the participants and the sampling and recruitment methods provided in this chapter. Three data collection methods were engaged, a survey, interviews and focus groups, and each of these is described in detail. This chapter also specifies the data management and analysis methods utilised including the use of electronic data management and analysis programs.

Methodology

This project was originally conceived as a mixed methods study with a small 'quantitative' arm comprised of closed-ended online survey questions for specialist nurses and a larger 'qualitative' arm involving individual and focus group interviews with specialist nurses and qualitative survey questions for treatment team members. The qualitative arm of the study was to be guided by the Interpretive Description methodology. The closed-end survey questions aimed to gather information from the specialist nurse sample to determine their education and employment history, and scope of practice that had never before been captured. An online survey was deemed the most efficient way to collect this information from participants rather than during an interview or focus group. Described in greater detail later in this chapter, the survey was also used as a method to collect qualitative data from treatment team members who may have been difficult to recruit to interviews or focus groups. . Given that the purpose of the 'quantitative' survey data was to 'describe' the specialist nurse sample, it was deemed to be in keeping

with the methodological approach of this qualitative study. Hence, an Interpretive Description methodology was adopted for the whole study, the rationale for which is explained below.

Interpretive Description

Interpretive Description (ID) is a relatively new qualitative methodology aimed at generating knowledge for clinical application within applied health disciplines (Thorne, 2008). Born of a need to generate nursing knowledge without the confines of strict adherence to traditional qualitative methodologies such as phenomenology, grounded theory and ethnography, Interpretive Description is grounded in the epistemological foundations of nursing, adheres to the systematic reasoning of the nursing discipline and yields applicable knowledge (Thorne, Kirkham, & Macdonald-Emes, 1997). Where other methodologies aim to generate theory or to describe only, Interpretive Description aims to interpret findings ready for clinical application. Thorne, Kirkham, and O'Flynn-Magee (2004, p. 3) state that:

> "The foundation of interpretative description is the smaller scale qualitative investigation of a clinical phenomenon of interest to the discipline for the purpose of capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding".

Interpretive Description is suitable as the qualitative methodology of this research project given its endeavour to create practice knowledge. The generation of theory or description alone in nursing research means that research is often not translated into practice. Taking the further step of interpreting findings presents the outcomes of qualitative research in a more usable form. Interpretive Description extends beyond collecting and reporting data by constructing an interpretive account of what the identified themes signify and presenting this in a manner that is accessible to clinicians (Thorne et al,

2004).

Interpretive Description and nursing epistemology

Interpretive Description is a form of qualitative inquiry that allows nursing research to be based on nursing's philosophical core. As founder of Interpretive Description, Thorne claims that nursing disciplinary epistemology is a sound and meaningful basis for qualitative nursing research (Thorne, Stephens, & Truant, 2016). The philosophies of social scientists need not be borrowed when the philosophical basis of nursing can be used to guide research on nursing. Thorne recognised that conventional social science methodologies did not meet the disciplinary needs of nursing and identified the tensions associated with faithfully adopting conventional methodologies and trying to create research output that was useful to nursing (Thorne et al., 2016). Although Thorne concedes that the identification of exactly what nursing epistemology is remains a "work in progress" (Thorne et al., 2016, p. 454), she claims its existence upon the recognition of its members of a mutual and coherent understanding with identifiable shared elements consistent with this understanding. Despite the lack of definition of what nursing disciplinary epistemology entails, Interpretive Description recognises it as an effective theoretical scaffolding for the design of applied research (Thorne et al., 2016). This piece of research is about a nursing role and a methodology based on nursing knowledge and 'knowing' as a nurse is the most appropriate framework in which to collect, analyse and interpret its findings.

Scaffolding of the study

The initial stages of an ID study involve the construction of a 'scaffold' for the study, the initial position from which the study is designed and planned. Thorne (2008) identifies the key elements to a study

scaffold as the literature review and the 'theoretical forestructure'. Chapters 1, 2 and 3 of this thesis form the scaffold upon which this study was designed and planned. Chapters 2 and 3 presented reviews of the literature relating to the women's perspective of the specialist nurse role and the needs of women with gynaecological cancers. These reviews represent current knowledge of the specialist nurse role in gynaecological oncology which has only been investigated from the patients' perspective. The 'theoretical forestructure' is the second element of the study scaffold which requires the researcher to 'locate' themselves within the field. Thorne (2008) postulates that the theoretical forestructure in an ID study allows for explicit recognition of the researcher as the instrument. Chapter one of this thesis includes the theoretical forestructure of this study which locates the researcher's theoretical allegiances upon entry to the study, locates the researcher within the discipline of gynaecological oncology and their personal relationship to the study. The theoretical forestructure was written as part of the research proposal and completed before data collection commenced.

Trustworthiness and credibility

In their sentinel work on establishing trustworthiness in qualitative inquiry, Lincoln and Guba (1985) proposed four main criteria upon which this may be addressed - credibility, transferability, dependability, and confirmability. Over the years these criteria have been debated, adapted and alternative criteria developed (Polit & Beck, 2010). Polit and Beck (2010) combined and re-presented the criteria of Lincoln and Guba (1985) and others with a focus on strategies to reduce threats to the integrity of qualitative research. Whilst Thorne (2008) accepts that the employment of these techniques may enhance the credibility of the study, alternative methods for establishing the credibility of an Interpretive Description study are postulated – epistemological integrity, representative credibility, analytic logic, and interpretive

authority. Both the criteria of Thorne (2008) and Polit and Beck (2010) have been drawn upon to establish the trustworthiness and credibility of the methods, findings and interpretations of this study.

To increase the likelihood that credible findings and interpretations from this study would be produced, several techniques suggested by Polit and Beck (2010) were employed. The requirement for 'prolonged engagement' in order to understand the culture within which the participants of this study work, along with the establishment of trust, were enabled by the researcher's relationship to the field as described in the theoretical forestructure in Chapter 1 (Polit & Beck, 2010). Where 'prolonged engagement' provides scope, 'persistent observation' provides depth whereby the researcher can identify and focus on elements that are most relevant to the inquiry (Polit & Beck, 2010). Triangulation of sources and methods was employed in this study through the gathering of data from different key stakeholder groups and utilisation of three different data collection methods. The process of 'member checking' was employed through ongoing engagement with the data during the data collection period to confirm, test and explore interpretations with participants (Polit & Beck, 2010; Thorne, 2008). Triangulation confirms the credibility of data whereas member checking tests the credibility of interpretations (Polit & Beck, 2010). However, the process of 'member checking' can lead the researcher to draw misleading conclusions if participants are reluctant to disagree with the researcher or conspire to mislead the researcher (Polit & Beck, 2010). A process of searching for "disconfirming evidence" was undertaken throughout the data collection and analysis processes to identify opposing or alternative views (Polit & Beck, 2010, p. 501) to mitigate the formation of misleading conclusions through the member checking process.

Unlike the establishment of external validity in the positivist paradigm, the determination of transferability is dependent upon description of the time and context in which the research was conducted (Polit & Beck, 2010). In this study the term 'representation' is used not in a statistical sense but rather to demonstrate that participation was sought from all sub-populations between which variance may have existed. Dependability was sought through the process of 'auditing' both the research processes and the research products (Polit & Beck, 2010). A process of "peer debriefing" was conducted by the supervision team of this project across all stages, with the discussions and outcomes relating to all key methodological decisions documented and ratified by all parties (Polit & Beck, 2010, p. 502). An "audit trail" was established which included raw data, data reduction and analysis products, data reconstruction and synthesis products, process notes, proposals, and instrument development information (Polit & Beck, 2010, p. 498). The supervision team also tested that interpretations based on the data were logical, and appropriate analytic techniques and category labels were used, for the overall determination that the findings were grounded in the data.

Thorne (2008) suggested that consideration of credibility must extend beyond the adherence to methodological rules and determine what meaning can be made of the research outputs. Epistemological integrity must be demonstrated through consistency between the stated epistemological standpoint and the research question posed (Thorne, 2008). Representative credibility relates to consistency between the theoretical claims made and the manner of sampling (Thorne, 2008). Maximal variation, prolonged engagement, and triangulation of methods and sources are all purported by Thorne (2008) to improve representative credibility. The analytic logic of the study should be explicitly reported from the forestructure through to the interpretation and knowledge claims made. To this end, Thorne (2008) supports the generation of an audit trail and the reporting of verbatim accounts from the data to

corroborate interpretations. Interpretive authority is the extent to which a researcher's interpretations are trustworthy, providing a fair representation outside of their own experience (Thorne, 2008). The researcher maintained a reflexive journal throughout the project as a means of accounting for the judgements and interpretations made of the data.

The procedures through which trustworthiness and credibility were sought in this study are described in greater detail in the context of the methods to which they apply below.

Methods

This section of the chapter describes the methods used in the execution of this Interpretive Description study including ethics approval, participant selection, data collection and management, and analysis methods.

Ethical approval

Ethics approval for this project was sought and granted by the Monash University Human Research Ethics Committee (MUHREC) in January 2016 (see approval in Appendix I). An urgent amendment to the approval was sought and approved in April 2016 to include participants from New Zealand in the study. This study was considered low risk in nature and required completion of a low risk MUHREC application. It was anticipated that this research would not cause discomfort to the participants beyond that caused by the

commitment of their time. It was posited that focus group and interview participants may feel tired after their contribution, particularly when scheduled among other conference activities. As the participants of the focus groups and interviews were asked to identify challenges in their work this did conjure some emotion for participants though these participants did not require further support upon enquiry at the end of the interview.

Participant selection

Participants

This study sought participants identifying themselves as gynaecological oncology specialist nurses or other members of gynaecological oncology treatment teams. Gynaecological oncology specialist nurses were invited to participate anonymously in a survey and/or to be interviewed or participate in a focus group. Other members of gynaecological oncology treatment teams were invited to respond anonymously to a survey.

It was known prior to commencement of the study that the specialist nurse role in gynaecological oncology was practised under varying role titles within Australia, including but not limited to: clinical nurse specialist, clinical nurse consultant, cancer nurse coordinator. This study required participants to self-identify as specialist nurses on the basis that no formal role definition exists. However, this study is about a 'super-numery' role that fulfils patient needs outside of standard patient care provided by ward/unit nurses. With an understanding of nursing award structures in Australia, participants' role title may be 'clinical nurse specialist' (awarded to them in recognition of their seniority and experience) yet their role does not involve work beyond standard patient ward/unit care. For inclusion in this study as a 'specialist nurse', participants must have fulfilled a role on a full time, part-time or casual basis that performed

supportive care functions beyond standard patient ward/unit care. Nurses who expressed an interest in being interviewed or participating in a focus group were screened by the researcher to determine if their role fit the criteria. Such screening could not be achieved for anonymous survey respondents however the lines of questioning within the survey served to identify the scope of practice of the respondent and were thus subject to analysis and interpretation according to the overall project aim to define the specialist nurse role in gynaecological oncology.

Other members of gynaecological oncology teams who participated in the survey were able to select from a list of occupations to identify themselves or select 'other' if their specific role was not listed. Participants identified themselves as nurse practitioners, nurse managers, nurse educators, registered nurses (various roles), gynaecologists, gynaecological oncologists/fellows/registrars, medical oncologists/fellows/registrars, radiation oncologists, social workers, dieticians, psychologists, researchers/ research assistants, study coordinators, data managers or cancer geneticists. This group of participants are referred to herein as 'Treatment team members'.

Initially this study was to include participants from Australia only and the original ethics application reflected this. However, two weeks before data collection was due to commence the researcher was contacted by specialist nurses from New Zealand who requested that the study be extended to include New Zealand gynaecological oncology health professionals. As discussed in the 'theoretical forestructure' section of Chapter 1 of this thesis, the inclusion of gynaecological oncology health professionals from New Zealand was considered when this study was being designed however the researchers did not feel that there was a mandate to do so until the matter was instigated by the New Zealand nurses. Similarities in health care provision across the two countries made this request feasible and expanded the breadth and depth of the study.

Women with gynaecological cancers were not included in this study as their experiences of specialist nursing care had been sought in other studies included in the systematic review in Chapter 2. Likewise, studies investigating the effectiveness of specialist nursing care on the quality of life, satisfaction with care and psychological outcomes of women with gynaecological cancers were evaluated in another review (Cook et al., 2015).The decision to excluded women with gynaecological cancers in this study was carefully considered by the researcher and supervision team. Women with gynaecological cancers are a vulnerable group and their engagement in research must be sought only where significant benefit to the group is envisaged. It was recognised that there is a need to engage women with gynaecological cancers in research that tests the efficacy of specialist nursing care or interventions such as guidelines for practice or a model of care. However, before such interventional research can be undertaken, or guidelines or models of care developed, the gynaecological oncology specialist nurse role must first be defined. Whilst not conclusive, the two systematic reviews, along with the integrative review included in Chapter 3 of this thesis considering the needs of women with gynaecological cancers, bring the perspectives of women with gynaecological cancers on the specialist nurses' role that can be deemed adequate for the purpose of this study.

Sampling

Convenience and snowball sampling were employed to recruit specialist nurses and members of the treatment team to both the survey, and interview and focus group arms of the study. Throughout the data collection period purposive sampling was also employed in the recruitment of interview participants to seek representation from all states, regions and sectors of Australia and New Zealand's healthcare systems. Of the survey and interview/focus group participants, all states and territories of Australia were represented except for the Northern Territory. It was confirmed during an interview with a specialist nurse

from South Australia that women with gynaecological cancers from the Northern Territory are treated in either South Australia or Queensland as comprehensive gynaecological oncology services are not offered in the Northern Territory. Survey and interview participants from New Zealand identified themselves as working within four of New Zealand's 16 regions - Auckland, Canterbury, Waikato and Wellington. New Zealand women with gynaecological cancers living outside of these regions travel to these centres for their treatment. Survey respondents identified their workplaces as located in metropolitan, regional or rural settings though there were no respondents who identified their workplaces being in remote locations. Interpretive Description also promotes the use of theoretical sampling. Derived from grounded theory methodology, theoretical sampling involves sampling based on the evolving theoretical variations in the data (Thorne, 2008). Theoretical sampling was employed in the follow-up interview of two focus group participants to further investigate issues arising during the focus group discussions.

Sample size

Initial sample size targets for participation in the survey were difficult to determine based on a lack of records kept on the number of specialist nurses practising in gynaecological oncology in Australia and New Zealand. National nursing registration in Australia does not have a suitable category to identify as a gynaecological oncology nurse and nurses in this field are likely to identify themselves as either surgical nurses or oncology nurses (King et al., 2008). Gynaecological oncologists and gynaecological oncology specialist nurses are the only 'designated' workforce caring for women with gynaecological cancers. Other disciplines have a designated role to play in their care but few will see it as career-defining (King et al., 2008). King et al. (2008) stated that 129 full time equivalent (FTE) health professionals including gynaecological oncologists, medical oncologists, radiation oncologists, pathologists, specialist nurses and allied health professionals were dedicated to the care of women with gynaecological cancers in Australia in 2008. This number did not include the nurses providing direct patient care for women with

gynaecological cancers. They predicted that the number of gynaecological oncologists practicing in Australia in 2015 would be 52, an increase of around 60 per cent from 33 in 2008 (King et al., 2008). Applying this rate of increase to the gynaecological oncology workforce figures of 2008, it could be estimated that this population would grow to 206. This population estimate does not include nurses other than specialist nurses who also interface with the specialist nurse role and whose perspectives were also sought in this study. At the time of the gynaecological oncology workforce survey (King et al., 2008), 11 specialist nurses were identified as working in centres treating women with gynaecological cancers. The extrapolation applied above to estimate the gynaecological oncology workforce population indicated that approximately 17 specialist nurses would be working in Australia around the time of sampling. It was thus estimated that sample size for the focus groups and interviews would be 15+ specialist nurse participants and the same number of specialist nurses would participate in the survey. This sample size estimation was based on the Australian workforce figures only and calculated before New Zealand participants were included in the study. Their inclusion accounts for the greater number of actual specialist nurse participants. For the section of the survey relevant to treatment team members, representation from sub-groups of treatment team members, states/territories/regions and sectors was pursued to consider similarities and differences among these groups.

Interpretive Description avoids using 'data saturation' as a justification for sample size based on the premise that individuals will present infinite variation in relation to their experiences (Thorne, 2008). The decision to cease recruitment of new participants was made when no new responses had been received for three weeks following the issue of final reminders to CNSA and ANZGOG members and the aims relating to determination of variance in practice had been met. As one of the aims of this project was to determine similarities and differences in practice among gynaecological cancer specialist nurses within and between organisations, sectors and jurisdictions, sampling was focused on ensuring representation

for all afore-mentioned sub-populations. Representation from all disciplines within a gynaecological oncology multidisciplinary team was also sought to ensure a wide range of perspectives on the role were gained. Additionally, variation within categories and themes were observed during the data collection period signifying that although maximal variation cannot be guaranteed from a sample only, sufficient data had been collected to provide differing perspectives of the role.

Recruitment

The first line of recruitment for the survey, focus groups and interviews was via the membership of two professional organisations – Australia and New Zealand Gynaecological Oncology Group (ANZGOG) and Cancer Nurses Society of Australia (CNSA). Members of each of these groups were invited to participate in the study via e-mail (Appendix II Participant invitation). The electronic invitation contained hyperlinks to the survey along with hyperlinks to secure, password-protected, Google docs that enabled the potential participant to register their interest to be interviewed, participate in a focus group, or receive further information about the study. Participants were then contacted by the researcher to determine if the individual met the criteria to participate in an interview or focus group and appropriate arrangements made if so.

Promotion of this project also occurred in the form of presentations delivered by the researcher at the 2016 annual conferences of ANZGOG and CNSA held in April in Double Bay NSW and in May in Cairns QLD respectively. The presentations covered a short introduction of the researcher and their motivation for conducting the study, background to the study, a review of the literature and systematic review, the aims of the study and possible outcomes of the study. A brochure explaining the study and providing links to complete the survey or register their interest in participating in a focus group or interview (Appendix III Advertising brochure) was placed on the seats of delegates at the conferences. Delegates were

encouraged to take copies of the brochures back to their workplaces as a snowballing strategy. Participants were also asked to forward the email received from their professional organisation (in its entirety, including attachments) to colleagues who may not have been members of CNSA or ANZGOG but would be suitable participants, as an additional snowballing strategy.

It was originally planned that in-person recruitment would occur at the conferences with the researcher 'roaming' with a portable device during the conference breaks, offering delegates the opportunity to complete the survey on the spot. It was also planned that the researcher would offer the survey to be taken as a short, structured interview for treatment team members. However, this recruitment strategy was abandoned as the researcher found that delegates were more interested in eating and networking during the breaks and were not responsive to this method of recruitment. Provision was also made in the approved recruitment strategy to invite specialist nurses and treatment team members who were personally known to the researcher but may have not members of ANZGOG or CNSA however on the two occasions that this strategy was employed the potential participants had already been made aware of the study through their professional memberships.

Non-participation

The survey contained a screening question to determine if respondents worked in the field of gynaecological oncology or cared for women with gynaecological cancers. Six survey respondents answered 'no' to this question and thus proceeded to the end of the survey. One potential participant registered their interest in participating in a focus group but subsequent emails with this nurse determined that they did not meet the criteria for inclusion. This nurse was invited to complete the survey and to observe the focus group for which they had expressed their interest in. Similarly, two nurses who registered their interest in being interviewed were found to not meet the criteria for inclusion and were

also invited to complete the survey as treatment team members.

Data Collection

Data were collected via three methods: survey, individual interviews and focus groups. Explanatory statements were provided to all participants and written consent gained where required.

Explanatory statements and consent

Explanatory statements and consent forms were provided to all interview and focus group participants prior to participation (see Appendices IV, V). Participants returned their consent forms in person prior to commencement of the interviews or scanned their signed form and sent it via email. Electronic consent forms were stored securely on a Monash University password-protected computer drive and backed-up regularly. Consent forms completed manually were stored in a locked filing cabinet in the Monash University Nursing and Midwifery Peninsula campus PhD room and were also scanned and filed electronically. One participant had not returned their consent form at the time of a telephone interview but stated that they had read the explanatory statement, provided recorded verbal consent, and retrospectively emailed their signed consent form to the researcher. Survey participants received a copy of the relevant explanatory statement as an attachment to the invitation email (Appendix VI). Consent was implied in the voluntary completion of the electronic survey.

Survey Data Collection

An electronic survey with two main question streams was developed to address the aims of describing

the specialist nurse role and determining the experiences and perceptions of treatment team members regarding the specialist nurse role (see Appendix VII Survey transcript). The survey was created utilising Qualtrics software (Qualtrics LLC, 2015a) and data were collected via this platform. Participants identifying themselves as specialist nurses proceeded down one question stream and those identifying themselves as treatment team members proceeded down another. The 'specialist nurse' arm of the survey consisted of predominantly closed questions aimed at describing the demographics, employment conditions and scope of practice of the specialist nurses. The 'treatment team' arm of the survey comprised mainly of open-ended questions aimed at determining this group's experiences and perceptions of the specialist nurse role in gynaecological oncology. Data on 'what' gynaecological oncology specialist nurses do had not been collected prior to this study, and a survey was deemed the most efficient way of collecting this data. It is acknowledged that the most conventional ways to capture individual or group experiences and perceptions of a phenomena in a qualitative study is to conduct interviews or focus groups (Thorne, 2008). The unconventional decision to utilise a survey as a method of data collection in this qualitative study was based on two reasons. Firstly, the aim to describe gynaecological oncology specialist nurse practice required the collection of a significant amount of demographic, employment and scope of practice information that was most efficiently captured in a survey format. This data was collected for descriptive purposes and was not intended to be analysed quantitatively to infer relationships or determine variance. Secondly, there was concern that the recruitment of team members from the medical discipline for participation in interviews or focus groups would be very difficult. Medical specialists were considered busy professionals and, given that the study was about another discipline and financial reimbursement for their time was not possible, an online survey was deemed to be the most time and cost-effective way of accessing this group. The questions asked of the treatment team within the survey were qualitative in nature and what would have been asked in an individual or focus group interview. It is acknowledged however that '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.

The survey was open to participants from April 14, 2016 to August 21, 2016 and was closed three weeks after a final reminder was sent to ANZGOG and CNSA members. No further responses had been received in the two weeks prior to closure. The survey could be taken by participants at their convenience on any compatible personal computer or hand-held device, accessed via a link sent in the recruitment emails or manually typed in to a browser from one of the printed brochures. The survey was developed using Qualtrics software (Qualtrics LLC, 2015a) under a license held by the Faculty of Medicine, Nursing and Health Sciences of Monash University. Qualtrics offers a function to anonymise participants' responses and this was put in place to assure participants' privacy and confidentiality (Qualtrics LLC, 2015b). As the survey was not distributed by Qualtrics, they did not have access to any personal details of participants (Qualtrics LLC, 2015b). As the gynaecological oncology workforce in Australia and New Zealand is relatively small and well known to each other, including the researcher, anonymity of the survey was employed to mitigate the possibility of any researcher bias that may have resulted.

The survey was piloted to determine face and content validity. Several Monash University academic staff with knowledge and experience in nursing specialisation, and a nursing expert in the field of gynaecological oncology, piloted the survey. The design of the survey was also reviewed by a Monash University statistician with minor modifications made. During piloting, the survey took approximately 10-20 minutes for testers to complete working down various pathways. As this was a qualitative study and the purpose of the survey was to describe and seek experiences and perceptions, it was not necessary to determine statistical reliability or internal, external or construct validity of the tool.

Focus group data collection

Focus group interviews are useful in discovering new information and obtaining different perspectives on a topic (Schneider & Whitehead, 2016). Data can be gained from both the contributions of individual focus groups members and the interactions that occur between them (Schneider & Whitehead, 2016). Focus group interviews were selected as a data collection method in this study to allow the specialist nurses the opportunity to interact and discuss the questions put to them as a group. It was a rare opportunity for many of the specialist nurses to connect with their peers as many didn't have contact with other gynaecological oncology specialist nurses on regular basis. The focus groups were aimed at capturing the specialist nurses' perceptions and experience of their role and how they saw the role in the future and were guided by semi-structured interview schedules. Participants were free to interact with each other and ask questions of one another within the rules provided to them before the commencement of the group interview (see Appendix IIX Focus group schedule).

The two focus group interviews were held at the annual conferences of ANZGOG and CNSA held in April and May 2016 respectively. The group interviews were conducted in pre-booked conference rooms and audio recorded with the permission of participants. A co-facilitator assisted the researcher at each of the focus group interviews, taking notes and making observations, and assisting the facilitator and participants as required. In the first focus group the co-facilitator was the chief supervisor of this project. A member of the audience from the presentation made earlier in the day at the conference by the researcher, requested that they be an observer in the focus group and was granted permission by the participants. In the second focus group the co-facilitator was one of the participants in the first focus groups, and also the chair of the national gynaecological oncology specialist nurse practice network. Permission was also sought from participants of the second focus group to allow three interested individuals to observe the focus group interview. The observers were known to the participants but did

not themselves meet inclusion criteria to participate. The focus group interviews ran for approximately 90 minutes each and were guided by the focus group schedule provided in Appendix IX.

Interview data collection

Interviews enable the researcher to enter the participant's world and gain a deep insight into their experiences and perceptions (Schneider & Whitehead, 2016). One-on-one interviews were conducted in this study to enable the experiences and perceptions of the specialist nurses to be explored in greater depth. Individual interviews were conducted either in person at a location nominated by the participant or via telephone and were audio-recorded with the permission of the participant. Interviews were semi-structured to ensure that the research objectives were covered but also allowed flexibility for participants to contribute their own thoughts and experiences (Schneider & Whitehead, 2016). An interview schedule was used to guide the interviews (see Appendix IX Interview schedule). Like the focus groups, these interviews were aimed at capturing the specialist nurses' perceptions and experiences of their role but offered those who could not attend a focus group the opportunity to contribute to the study. Data collection and preliminary analysis occurred concurrently to allow for member checking of emerging themes with subsequent interviewees. Individual interviews were also offered to those who contributed to focus groups to allow further exploration of emerging themes, which also afforded the participant the opportunity to share what they may not have felt comfortable sharing as a group. Two specialist nurses participated in both a focus group and individual interview. Interviews ranged in duration from approximately 30 to 90 minutes.

Data Analysis

The data management, verification and analysis methods employed for the three data sets are detailed in this section of the chapter. Responses to the closed-ended and open-ended survey questions were managed and analysed separately as described below.

Survey data

Data management – Closed-ended questions

Data collected through the Qualtrics online survey platform are to be stored within that system until completion of the project. Qualtrics is a 'software for service' platform for creating and distributing online surveys (Qualtrics LLC, 2015b). The platform can record response data, perform analysis and report on the data. Data generated through the platform is owned and controlled by the customer, in this case the Monash University Faculty of Medicine, Nursing and Health Sciences (FMNHS) and the user (the student researcher) (Qualtrics LLC, 2015b). Qualtrics only uses the data to perform the functions of the service, for example creating reports (Qualtrics LLC, 2015b). Thus, the survey data collected can only be accessed by the individual issued a user name and password by FMNHS, in this case, the student researcher. Data generated through this survey is stored in the Qualtrics Australia/Pacific region data centre (Qualtrics LLC, 2015b). Qualtrics have stringent security measures in place to protect and ensure the reliability of the data. Servers are protected by high-end firewall systems and vulnerability scans are performed regularly and complete encrypted backups are performed nightly (Qualtrics LLC, 2015b). Whilst the survey remained opened, reports were run on a regular basis to check participation rates and determine representation from jurisdictions and disciplines within multidisciplinary teams. Upon closure of the survey, data were exported to IBM Statistical Package for the Social Sciences (SPSS) v.23 for analysis.

Data management – Open-ended questions in NVivo

As for the responses to the closed-ended survey questions, responses to the open-ended questions were monitored in Qualtrics (Qualtrics LLC, 2015a) until closure of the survey. The Qualtrics license held by FMNHS does not allow for the direct import of Qualtrics data to NVivo Pro v.11 (QSR International Pty Ltd, 2016). Thus, the open-ended question data were first exported to Microsoft Excel 2013 and then imported from Microsoft Excel 2013 to NVivo Pro v.11 where an inductive content analysis was undertaken.

Data verification – Closed-ended questions in SPSS

SPSS v23 was utilised to manage and analyse the responses to closed-ended questions from the online survey. Data were exported from the Qualtrics survey platform to SPSS v.23 however the design of some questions in Qualtrics created unusable outputs in SPSS v.23 and a manual input and coding of data in SPSS v.23 was required for some questions. All manually entered data were audited by the Chief Supervisor of this project. A total of 10 questions required manual input of data and were audited by the Chief Supervisor (MMc) with the assistance of the researcher on March 9, 2017. Each manually entered variable was examined by MMc and frequencies verified. The audit process revealed two single manual data entry errors that were rectified immediately. In addition, data exported directly from Qualtrics to SPSS v.23 were randomly audited at the rate of five responses per 34 (14 per cent) with no errors found. A copy of the verified SPSS data file was kept on a Monash University licensed version of LabArchives, a secure, electronic data storage platform. The filing of data in LabArchives served as both a secure back-up and a means of secure access to the data for the supervision team in preference to the emailing of data.

Data verification – Open-ended questions in NVivo

Data exported from Qualtrics, via Microsoft Excel 2013, to NVivo Pro v.11 were cross-checked via use of the unique ID allocated by Qualtrics to determine completeness of the data transfer. All data were successfully transferred between programs. A copy of the verified NVivo Pro v.11 data file was stored in LabArchives for access by the supervision team as required.

Data analysis – Closed-ended questions in SPSS

The verified data file was used to generate frequencies and cross tabulations for comparisons between subgroups. As this is a qualitative study, the purpose of the closed-ended survey data questions was to describe the specialist nurse and treatment team samples and their current practices, hence frequencies were derived from the data. The verified SPSS v.23 data for given variables was also exported to Microsoft Excel 2013 to generate graphic outputs.

Data analysis – Open-ended questions in NVivo

The responses to open-ended questions answered by treatment team members were subjected to a qualitative inductive content analysis. These responses were variable in length ranging from one sentence to essay-like responses and did not suit thematic analysis as was originally planned. An inductive content analysis method was thus 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). In an inductive content analysis, categories are derived from the raw data (Elo et al., 2014). The imported data were automatically coded by NVivo v.11 to the questions to which they

pertained and subsequent coding occurred under these banners. Sentences were selected as the unit of analysis as paragraphs often contained more than one meaning and words alone lacked context. Some sentences were coded to more than one category where more than one meaning was evident. During the organisation phase of data analysis, participant responses to each open-ended question were extracted and coded by the researcher to minor categories in NVivo v.11 according to meaning. The frequency of items coded to each category was recorded to determine the proportion of participants providing given responses. Minor categories of similar meaning were then grouped to form major categories.

The 'trustworthiness' of this process was examined through consultation with the supervision team (Polit & Beck, 2010). The minor and major categories were presented to the supervision team along with extracts of data upon which the minor categories were formed. Over two meetings, the supervision team 'audited' the inductive content analysis process, discussing and verifying the minor and major categories developed by the researcher against the data extracts (Polit & Beck, 2010). Consistency in the naming and description of categories formed under each topic/question was ensured where meaning was the same. For example, several treatment team members identified that coordination of care was both an important aspect of the specialist nurses' role in relation to both the woman with a gynaecological cancer and her family/carers, thus 'coordination of care' was a minor category for both questions. The process of member checking to determine the credibility of findings was not possible for this data set given that the survey was anonymous. Triangulation of sources or "person triangulation" was possible between the sub-groups of the survey group (Polit & Beck, 2010, p. 497). Medical specialists, nurses and allied health professionals offered different perspectives of the phenomenon under investigation, and professional designations were applied to reported data extractions to allow for comparison and triangulation. A description of treatment team participants was reported including professional designation, sector of the health care

system they worked in, the setting of employment for example hospital or private practice, the geographical location of their work according to country, state/territory/region, and if they worked in a metropolitan, regional, rural or remote area. Description of the sample allows the reader to determine transferability of the results (Elo et al., 2014; Polit & Beck, 2010). The results were reported in tables that included the major category, the minor categories upon which it was formed, and participant data extracts illustrating the categories.

Interview and focus group data

Data management – Interview and focus group data

All individual and focus group interviews were audio recorded and the sound files stored within LabArchives and on a password protected Monash University system computer. Audio recordings were either transcribed verbatim by the researcher or a professional transcription service under a non-disclosure agreement. Electronic copies of the transcripts were also stored in LabArchives and on a password protected Monash University system computer. Transcribed data in the form of Microsoft Word 2013 documents were imported directly into NVivo Pro v.11. The NVivo Pro v.11 file and subsequent versions were securely stored in LabArchives and on a password protected Monash University system computer.

Data verification – Transcribed individual and focus group interviews

The accuracy of all transcripts generated by the professional transcription service was verified by the researcher by listening to the audio-recording whilst reading through the transcript and making

corrections as required. Audio recordings transcribed by the researcher were listened to several times by the researcher to ensure accuracy of the transcript. During this process all identifying data were removed from the transcripts and the participants assigned a pseudonym relating to the interview type and number. For example, interview participant four was assigned the pseudonym IP-04 and participant three in focus group two, FG2-P03. Copies of the de-identified interview and focus group transcripts were confidentially emailed to each of the interview and focus-group participants for verification. Participants were offered the opportunity to withdraw any aspect of their contribution or provide additional commentary via email. One participant withdrew some sections of their interview and provided additional commentary to clarify their meaning in some sections of the transcript. Other participants made brief comments about their experience of being involved in the study or offered additional information supporting their interview or focus group contribution.

Data analysis – Interview and focus groups

Preliminary analysis of emerging categories and themes were conducted as the data were collected and transcribed. A reflexive journal was kept by the researcher during this period, with a particular focus on recording and reflecting on their response to data that attracted their attention, as counselled by Thorne (2008). The researcher was careful to document why the data attracted their attention, whether it was unexpected, contrasted other data, or confirmed other data. This process enabled the researcher to perform member checks on emerging categories and themes in subsequent interviews to test and expand on the researcher's reflexive conceptualisations.

Individual and focus group interview transcripts were imported into NVivo Pro v.11 and subjected to a thematic analysis. The process of coding data within NVivo Pro v.11 commenced upon completion of data collection. Initially, the process of 'open coding' as described by Thorne (2008) was applied to each individual interview and focus group transcript, and the minor categories within each interview identified. These early categories within each interview were presented, along with participant extracts, to the supervision team and discussed at length. It became apparent to the researcher and supervision team at this point that the interviews and focus groups contained some data relating to demographics, scope of practice and employment conditions of the participants that was not suited to thematic analysis. This data was however relevant to the overall project and was separately coded and subjected to an inductive content analysis. This analysis was conducted according to the procedure for the open-ended survey question data and reported as the characteristics of the sub-sample of specialist nurses.

The openly-coded data pertaining to the experiences and perceptions of the specialist nurses within each interview were subjected to a second layer of coding whereby similar or related categories across interviews and focus group data were grouped. Other categories across the interview and focus group data that contrasted these categories were grouped with them. The decision to analyse the interview and focus group data together was made at this point as the categories identified in each were similar. Should the individual and focus group interviews have produced unrelated categories, these would have been analysed separately. Analysis of the interactions between focus group participants was however conducted. This analysis revealed categories that related to categories identified within individual interviews and these were thus grouped. Outlying categories that may have been the view of a single participant on a topic not considered by others or not related to the research topic, were not eliminated

and were not forced to fit into these groupings, remaining as outlying categories with their relevance to be determined at a later stage.

The similar and contrasting grouped categories were then subjected to a second layer of coding whereby minor themes were identified across the data. The minor themes, and the categories and extracts from which they were derived, were tested with the supervision team during a data analysis meeting. Attention was paid to contrasting themes and whether these should be presented as standalone themes or be included within the more dominant theme. As the contrasting themes were strong in themselves they remained standalone themes but remained grouped with their counter-theme. Some outlying categories fit within the minor themes and others remained outlying but again not eliminated. In a concept mapping exercise, related and contrasting minor themes were then grouped into major themes and a model that indicated the relationship between the major themes was derived. The map of major themes, and the minor themes from which they were derived, was again tested for confirmability and dependability by the supervision team during an analysis meeting. The remaining outlying categories were eliminated on the basis that they were not relevant to the research questions being addressed.

Final layer of analysis – integration and interpretation

The major findings from the analyses of each data set were triangulated and conceptualised in a model. Thorne (2008) determines that the final analytic process of an Interpretive Description requires the conceptualisation and elucidation of the meta-messages of the final set of findings. Thorne (2008, p. 175) posits that Interpretive Description is a “meaning-making activity” that provides a “new, enriched or expanded way of making sense” of a phenomenon. Thematic threads throughout the literature, survey,

interview and focus group data were drawn together to form a conceptual model. The model portrayed the gynaecological oncology specialist nurse role from the perspective of all key stakeholders and identified the threats to the stability of the model. As for all other key analysis decisions and outputs made by the researcher, the model was reviewed by the supervision team who confirmed its representation of the synthesis of the major findings. Thorne (2008) defers to the work of Morse (1994) to describe the final step in the analytic process – re-contextualising. This process involves placing the new knowledge into the settings and contexts within which it applies and determining the implications of it.

Summary

Interpretive Description was chosen as the methodological approach for this study based on its aim to generate new knowledge for nursing practice. Two main participant groups, gynaecological oncology specialist nurses and all other members of a gynaecological oncology treatment team, were recruited to the study through two professional bodies. Three data collection methods, individual interviews, focus groups and an online survey, were employed to enable description of the specialist nurse role and to determine participants' experiences and perceptions of the specialist nurse role. Though unconventional in a qualitative study, the survey served to provide a detailed description of specialist nurses' work and gain the perspective of medical specialists who may otherwise have not committed the time to be interviewed or participate in a focus group. Data were managed within electronic programs and subjected to one of three analysis methods including descriptive statistics, inductive content analysis, and thematic analysis. The major findings of each data set were conceptualised in a model upon which the interpretation and discussion of this study were based.

Chapter 5: Survey results

Introduction

This chapter presents the results of the online survey completed by specialist nurses and other members of the gynaecological cancer workforces of Australia and New Zealand. The demographic data of all survey participants is presented along with the data collected from each of the two main participant groups. Participants identifying themselves as specialist nurses responded to a discrete set of questions relating to their demography, employment and scope of practice. The content of the responses was analysed within SPSS v.23 and Microsoft Excel 2013 and presented in this chapter. All other participants identified themselves as members of a gynaecological oncology treatment team and answered an alternative set of questions relating to their perceptions and experiences of gynaecological oncology specialist nurses. This set of questions included both closed-ended and open-ended questions that allowed for longer answers from participants. The responses to the closed-ended questions were analysed utilising SPSS v.23 and Microsoft Excel 2013 and a content analysis of the open-ended question responses was undertaken within NVivo Pro v.11. The results of each analysis are presented in this chapter.

Demographic data of whole survey sample

This section of Chapter 5 reports on the demographic results of the whole survey sample. Between April 13, 2016 and August 21, 2016, 123 responses were received to the online survey. Of these, six (n= 6) respondents identified themselves as not working in gynaecological oncology and were immediately directed to the end of the survey. A further fifteen (n=15) did not complete the survey in full to varying extents and their data were excluded from analysis. As the survey was anonymous and no identifying data was collected by Qualtrics, it could not be determined if any of these fifteen respondents had

recommenced the survey from another device and were thus excluded. As it was not compulsory to respond to all questions in the survey, completion of the survey 'in full' relates to the progression through the survey to the last frame which thanked the participant for their participation. Participants who completed the survey 'in-full', but did not answer all questions, were included in the analysis with the number of responses to each question reported.

Role in gynaecological oncology team

Of the 102 respondents who completed the survey in full and identified themselves as part of the gynaecological oncology workforce, 34.3 per cent (n = 35) identified themselves as gynaecological oncology specialist nurses. This substantially exceeded the predicted number of specialist nurses of 18, though that was based on specialist nurses working exclusively in gynaecological oncology. The remaining respondents, n= 67, identified themselves as members of the gynaecological oncology team. Collectively, medical professionals accounted for 22.5 per cent of respondents (n=26). Based on figures extrapolated from the gynaecological oncology workforce study by King et al. (2008), this represents about a 20 per cent response rate from this sub-group. The next largest group to have responded were nurses in roles other than specialist nurse roles accounting for 23.4 per cent of respondents (n = 24). This group included nurse practitioners, nurse educators, nurse managers and registered nurses. Respondents who identified themselves as registered nurses (n=13) were asked to further specify their role. Of the registered nurses, n=11 categorised themselves as chemotherapy nurses (n=6), ward-based nurses (n=3) and radiotherapy nurses (n=2). Participants identifying themselves as cancer service coordinators accounted for 7.8 percent (n=8) of the sample. Further responses to the survey by these participants indicate that they could have identified themselves as specialist nurses. The implications of this are discussed as a limitation of the study. Other groups who responded to the survey included allied health professionals accounting for 4.9

per cent (n=5) of the sample, and those in gynaecological cancer research-related roles representing 3.9 per cent (n = 4) of survey participants. Table 5.1 below shows the professional specialisation of respondents in relation to the country of work.

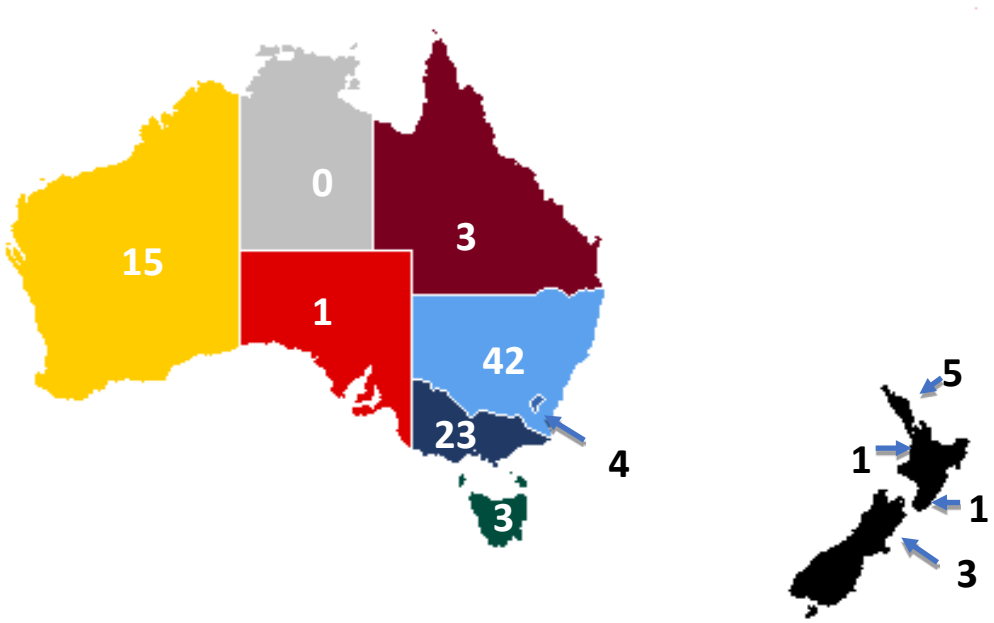
Table 5.1 Role in team according to country of work.

			Australia	New Zealand	Total
Role in team	Specialist nurse	Count	31	4	35
		% of Total	30.4%	3.9%	34.3%
	Nurse Practitioner	Count	3	0	3
		% of Total	2.9%	0.0%	2.9%
	Cancer Service Coordinator	Count	8	0	8
		% of Total	7.8%	0.0%	7.8%
	Nurse Unit Manager	Count	4	0	4
		% of Total	3.9%	0.0%	3.9%
	Nurse Educator	Count	4	0	4
		% of Total	3.9%	0.0%	3.9%
	Registered Nurse	Count	13	0	13
		% of Total	12.7%	0.0%	12.7%
	Gynaecological Oncologist/Fellow/Registrar	Count	6	2	8
		% of Total	5.9%	2.0%	7.8%
	Gynaecologist / Registrar/Fellow	Count	3	0	3
		% of Total	2.9%	0.0%	2.9%
	Medical Oncologist / Registrar/Fellow	Count	9	3	12
		% of Total	8.8%	2.9%	11.8%
	Radiation Oncologist	Count	3	0	3
		% of Total	2.9%	0.0%	2.9%
	Social Worker	Count	1	0	1
		% of Total	1.0%	0.0%	1.0%
	Dietician	Count	1	0	1
		% of Total	1.0%	0.0%	1.0%
	Psychologist	Count	3	0	3
		% of Total	2.9%	0.0%	2.9%
	Research-related role	Count	3	1	4
		% of Total	2.9%	1.0%	3.9%
Total		Count	92	10	102
		% of Total	90.2%	9.8%	100.0%

Country, states, territories and regions

Australia was represented in the survey results by 90.2 per cent (n=92) of participants and New Zealand by 9.8 per cent (n = 10) of participants. All states and territories of Australia were represented within the sample except for the Northern Territory which does not offer gynaecological cancer services. Respondents from New Zealand worked in the four regions where gynaecological cancer services were offered in New Zealand, being Auckland, Wellington, Hamilton and Canterbury.

Figure 5.1 Number of participants across states and territories of Australia and regions of New Zealand



Of the n=92 participants from Australia, n=91 specified the state or territory in which they worked. New South Wales was highly represented accounting for 41.2 per cent (n=42) of all survey participants. Victoria had the next highest number of participants representing 22.5 per cent (n=23) of the sample, followed by Western Australia with 14.7 per cent (n=15), Australian Capital Territory with 3.9 per cent (n=4), Tasmania and Queensland with 2.9 per cent (n=3) each and South Australia with 1 per cent (n=1) of the total number

of survey participants. Although skewed towards the Eastern seaboard of Australia, these response rates very closely reflect the distribution of gynaecological oncologists throughout Australia and may thus be deemed representative of gynaecological oncology services throughout the country (King et al., 2008). This could also have been a product of the recruitment strategy at conferences in Sydney and Cairns. Half of the participants from New Zealand were from Auckland (n=5) with representatives also from Canterbury (n=3), Wellington (n=1) and Hamilton (n=1). No report exists on the distribution of the gynaecological oncology workforce in New Zealand to compare this to.

Geographical location

Participants were asked to identify the geographical location of their workplace. Of the n=100 participants who responded to this question, 63.7 per cent (n=65) worked in a metropolitan area only, 26.5 per cent (n=27) worked in a regional area only and 4.9 per cent (n=5) worked in both metropolitan and regional areas. The remaining three (2.9 per cent) of respondents to this question identified as working in a rural area. Table 5.2 below indicates the number of participants working in each geographical location.

Table 5.2 – Geographical location of work according to country

		Geographical location of work				
		Metropolitan	Regional	Metropolitan & Regional	Rural	Total
Country of work	Australia	60	23	4	3	90
	New Zealand	5	4	1	0	10
Total		65	27	5	3	100

Sector

Survey respondents were also asked to identify the sector of the health care system that they worked in. As for the geographical location of their work, n=100 participants responded to this question. As shown in Table 5.3, most respondents (n=69, 67.6 per cent) specified that they work in the public health system only. Seven participants (6.8 per cent) worked in the private sector only, with n=13 (12.7 per cent) identifying that they worked in both the private and public sectors. Some Australian participants identified that they worked in the private not-for-profit sector (n=9, 8.8 per cent) or in both the public and private not-for-profit sectors (n=1, 0.98 per cent). The remaining respondent (n=1, 0.98 per cent) worked in both a university and the public health sector. The number of respondents working in each sector of the health system was also considered in conjunction with the role the respondent held within the treatment team as shown in Table 5.4. It was found that although some medical professionals (n=11) worked outside of the public system, the majority of specialist nurses worked exclusively in the public system (n=28) and only a small number outside of the public system (n=6). This indicates that women receiving medical treatment for gynaecological cancers outside of the public system may not have access to specialist nursing care.

Table 5.3 Sector of work and country worked in

	Sectors of healthcare system						
	Public	**Public and Private**	**Public and Private Not-for-profit**	**Public and University**	**Private**	**Private not-for-profit**	**Total**
Australia	61	12	1	0	7	9	90
New Zealand	8	1	0	1	0	0	10
Total	69	13	1	1	7	9	100

Table 5.4 Sector of work and role in team

		Sectors of healthcare system						
		Public	Public and Private	Public and Private Not-for-profit	Public and University	Private	Private not-for-profit	Total
Role in team	Specialist nurse eg CNS, CNC	28	2	0	0	2	2	34
	Nurse Practitioner	1	0	0	0	0	1	2
	Cancer Service Coordinator	7	0	0	0	0	1	8
	Nurse Unit Manager	1	1	0	0	2	0	4
	Nurse Educator	3	0	0	0	1	0	4
	Registered Nurse	9	0	0	0	0	4	13
	Gynaecological Oncologist/Fellow/Registrar	3	4	0	0	1	0	8
	Gynaecologist / Registrar/Fellow	1	0	0	0	1	1	3
	Medical Oncologist / Registrar/Fellow	8	4	0	0	0	0	12
	Radiation Oncologist	3	0	0	0	0	0	3
	Social Worker	1	0	0	0	0	0	1
	Dietician	1	0	0	0	0	0	1
	Psychologist	1	2	0	0	0	0	3
	Research-related role	2	0	1	1	0	0	4
	Total	69	13	1	1	7	9	100

This section of the chapter provided an overview of the 102 participants who responded to the online survey. Whilst the target of 100+ participants was met, the proportions of participants from each sub-group was not representative of the population upon which the estimation was made. The aim to gain participation from relevant sub-groups for the purpose of comparison was achieved. Participation came

from all states and territories of Australia and regions of New Zealand where gynaecological cancer services are offered, though most participants were from the Eastern seaboard of Australia. Most of the disciplines making up a gynaecological cancer multidisciplinary team were represented among the survey participants with the exception of pathologists. The majority of survey participants worked in the public health care sector. This was particularly true of the sub-sample of specialist nurses where 82 per cent of them worked in the public setting. Approximately two-thirds of the sample worked in metropolitan areas. As the overall gynaecological cancer workforce in Australia and New Zealand has not previously been measured, the size of the population from which this sample was taken is unknown and thus exact representation cannot be determined.

Specialist nurses working in gynaecological oncology

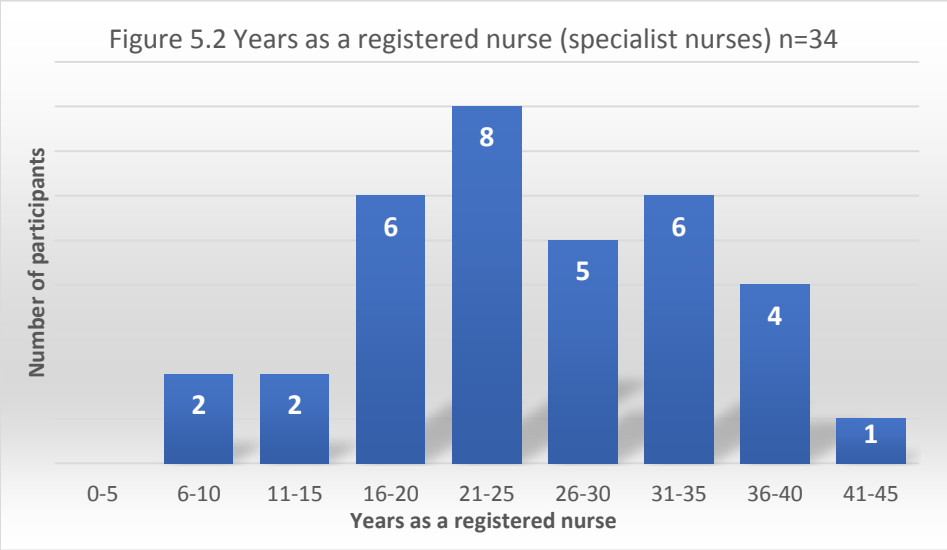
This section of Chapter 5 reports on the survey results of participants identifying themselves as specialist nurses. Although n=35 participants stated that they were specialist nurses and completed the survey 'in full', not all questions were answered by all participants and the sample size is specified for each question. This section reports on three main areas of data collected from the specialist nurses: additional demographic data, employment data and data relating to scope of practice.

Demographic data of specialist nurses

Years as a registered nurse

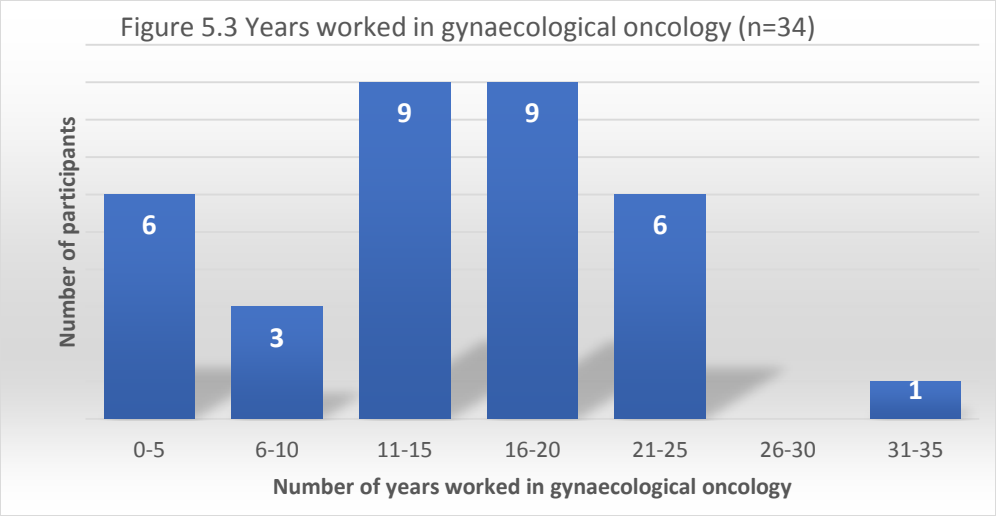
Thirty-four (n=34) specialist nurses responded to a question regarding how many years they had been registered as a nurse. Years as a registered nurse ranged from 6 years to 41 years with a mean of 25.68 years and a median of 24.00 years. The distribution of scores was slightly skewed to the right, as seen in

the histogram below, with more specialist nurses reporting greater years of experience as a registered nurse.



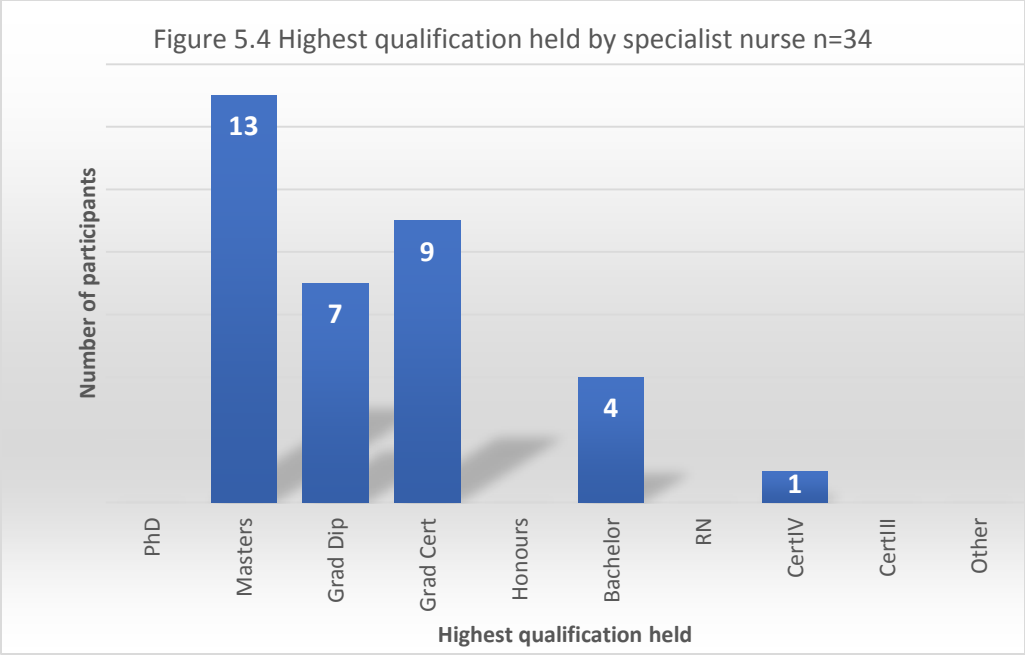
Years worked in gynaecological oncology

Specialist nurse participants were asked to state the number of years they had worked in the field of gynaecological oncology. The number of years the specialist nurses had worked in the field ranged from 1.5 years to 32 years. The participant who had worked in the field for 1.5 years also reported that they had 11 years of experience as a registered nurse. On average, the specialist nurses who responded to the survey had worked in gynaecological oncology for 14.65 years with a median of 15.00 years.



Highest qualification held by specialist nurses

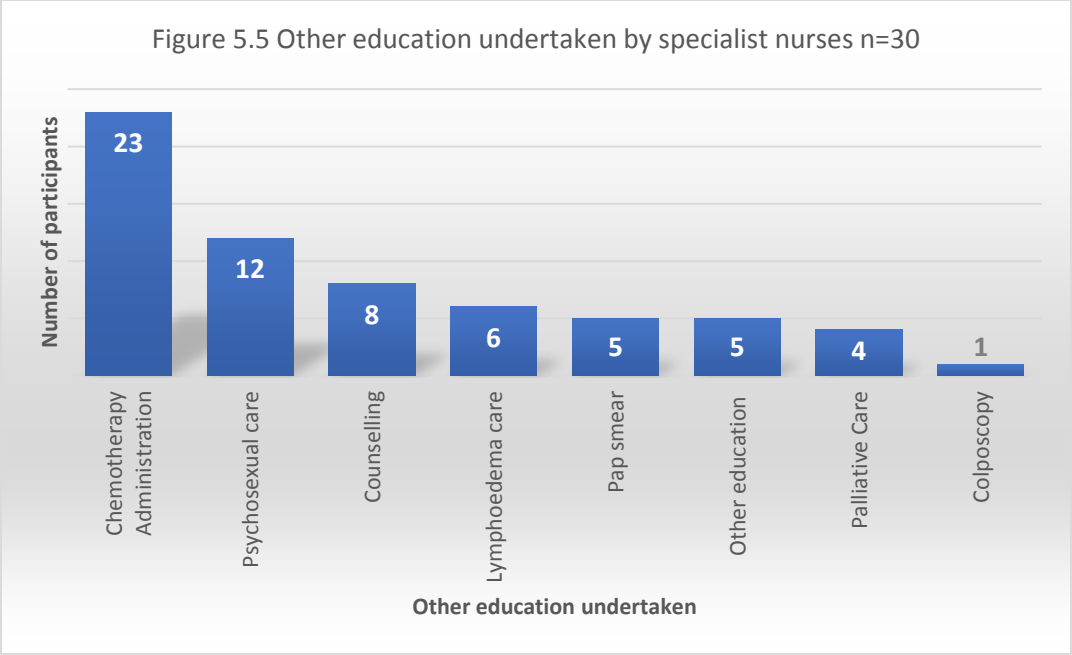
Specialist nurse were asked to select all relevant qualifications that they held from those listed. Presented in figure 5.4 below are the highest qualifications held by each of the n = 34 specialist nurses who responded to this question. Of the specialist nurses who responded to this question, n = 29 held a post-graduate qualification. Over a third of specialist nurses (n=13) had a master's degree. One participant (n=1) reported that their highest level of qualification was a certificate IV (diploma). This participant stated that their role title was 'Gynaeoncology liaison nurse'. Data pertaining to education that was currently being undertaken by participants was not collected.



Other education

As no gynaecological oncology-specific education pathway exists for nurses working in the field, specialist nurses were asked to identify other education they had undertaken in preparation for their role. A total of n=30 specialist nurses responded to this question. Education relating to chemotherapy administration (n=23) was the most popular type of additional education. Education regarding psychosexual care of patients had been completed by n=12 participants. 'Other education' was specified by the participants to be courses relating to cancer care, support group facilitation, stomal therapy and other online courses. Figure 5.5 shows the number of nurses who have completed given additional education in relation to their role.

Figure 5.5 Other education undertaken by specialist nurses n=30



Employment of specialist nurses

Several questions on the survey related to the employment arrangements and conditions of specialist nurses. As there are no national standards in Australia or New Zealand relating to the specialist nurse role in gynaecological oncology, the scope of practice of each specialist nurse is largely determined by their employing organisation.

Role title

Participants were asked to provide their exact role title as a free text entry which were subsequently coded. Table 5.5 below shows that there was variance in the role title between states and in New South Wales, Victoria and Western Australia there was also role-title variance within those states. All gynaecological oncology specialist nurses from New Zealand (n=4) who responded to the survey held the

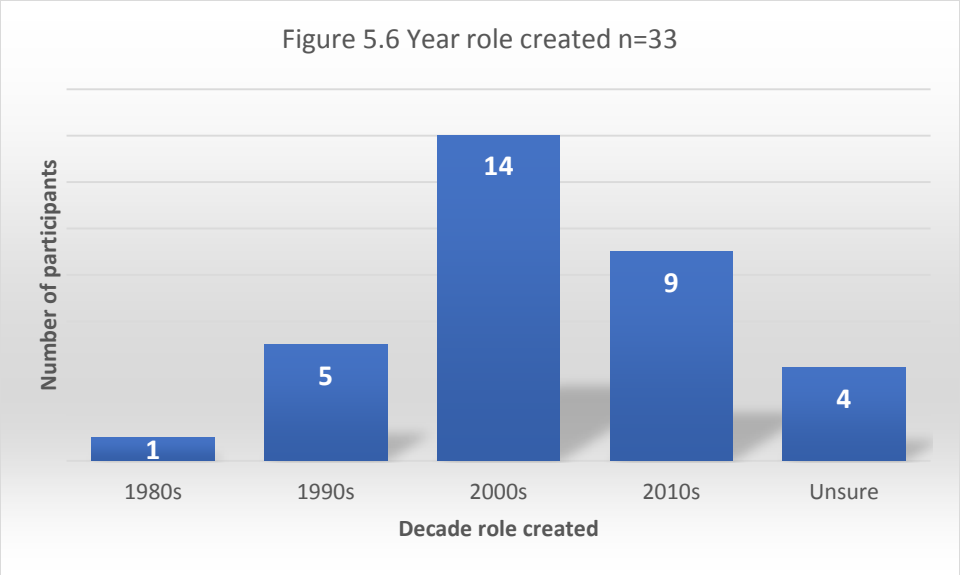
role title 'Clinical Nurse Specialist Gynaecological Oncology'. Table 5.5 below indicates the role titles held by nurses from the states and territories of Australia.

Table 5.5 Specialist nurse role titles according to state and territory of Australia.

Title of SN role	NSW	TAS	VIC	SA	QLD	WA	ACT	Total
Clinical Nurse Consultant Gynaecological Oncology	3	0	2	0	1	0	0	**6**
Gynae Oncology Support Nurse	0	0	0	1	0	0	0	**1**
Gynaeoncology Liaison Nurse	0	0	0	0	0	1	0	**1**
Clinical Nurse Consultant (combined or unspecified)	5	2	2	0	0	0	0	**9**
Clinical Nurse Specialist Gynaecological Oncology	0	0	1	0	0	0	0	**1**
Clinical Nurse Specialist (combined or unspecified)	6	0	1	0	0	0	0	**7**
Clinical Nurse	0	0	0	0	0	1	0	**1**
Nurse Coordinator Gynaecology	0	0	1	0	0	0	0	**1**
Nurse Coordinator (unspecified)	0	0	1	0	0	0	0	**1**
Cancer Specialist Nurse (combined)	1	0	0	0	0	0	1	**2**
Total	**15**	**2**	**8**	**1**	**1**	**2**	**1**	**30**

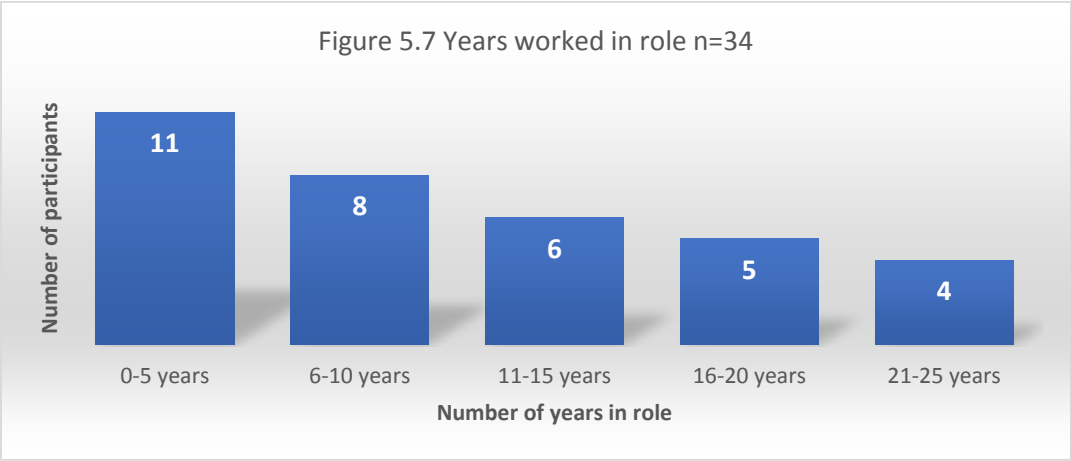
Year role created

The earliest specialist nurse role in gynaecological oncology to be captured by this survey (n=33) was created in 1987 in New South Wales, Australia. The most recent specialist nurse role in gynaecological oncology to be captured by this survey was created in 2015 in Wellington, New Zealand. The earliest specialist nurse role in gynaecological oncology in New Zealand to be captured by this survey was created in 1999 in Auckland. The histogram below (Figure 5.6) indicates that most of the specialist nurse roles in gynaecological oncology in Australia and New Zealand emerged in the 2000s to 2010s.



Years in role

Specialist nurse respondents to the survey provided free-text answers to the question relating to the number of years that they have worked in their current role (n=34). The mean number of years in the role was 10.13 years with a median of 9.00 years. The number of years worked in the role ranged from less than 1 to 25 years. Figure 5.7 indicates the number of years each specialist nurse had held their role.



Exclusivity of role to gynaecological oncology

Of the thirty-five (n=35) specialist nurse respondents, twenty (n=20, 57.1 per cent) reported that their role was exclusively gynaecological oncology related. Of the fifteen respondents (n=15, 42.9 per cent) who indicated that their role involved caring for patients with other conditions, five (n=5) also cared for patients with cancers other than gynaecological or breast cancer, two also (n=2) cared for patients with breast cancer, and four (n=4) cared for women with non-malignant gynaecological conditions. Other patients that specialist nurses with non-gynaecological oncology exclusive roles cared for were pre and post-natal women, IVF patients, radiology patients and those in the survivorship phase of illness.

Reporting line

As for the specialist nurse role titles, there was variance in the reporting lines of the specialist nurses between and within states, regions and sectors. Some roles sat within a clinical unit, others reported directly to executive management. As management roles and structures also vary between health care settings, respondents were asked to provide a free text entry to this question. Industrial awards and organisational structures were consulted to code responses to equivalent levels between the different states and regions. Of the respondents to this question (n=34), the majority (n=19) identified that they report to a nurse unit manager or nurse manager and their role was managed within a clinical unit. A further n=13 participants reported to divisional managers, operational managers, assistant director of nursing, director of nursing or equivalent. One remaining respondent held the title of 'Cancer specialist nurse' but reported to a clinical nurse consultant. Table 5.6 below indicates the variance in reporting lines between and within states and regions.

Table 5.6 Reporting lines for specialist nurses in Australia and New Zealand.

		State or territory of Australia							Region of New Zealand				
	Reports to	**NSW**	**TAS**	**VIC**	**SA**	**QLD**	**WA**	**ACT**	**Auckland**	**Canterbury**	**Waikato**	**Wellington**	**Total**
Specialist Nurse reports to:	Nurse Unit Manager / Charge Nurse Manager	6	0	4	0	0	0	0	0	1	0	1	12
	Nurse Manager	2	0	1	0	0	2	0	1	0	1	0	7
	Operational Nurse Manager	2	0	0	0	0	0	0	0	0	0	0	2
	Divisional Nurse Manager	2	0	0	0	0	0	0	0	0	0	0	2
	Assistant Director of Nursing	0	2	0	0	0	0	0	0	0	0	0	2
	Director of Nursing / Director of Clinical Services / Medical Director	2	0	1	1	1	0	0	0	0	0	0	5
	Manager of Specialist Clinics, Specialist Nurses and Specimen Collection	0	0	2	0	0	0	0	0	0	0	0	2
	Clinical Nurse Consultant	0	0	0	0	0	0	1	0	0	0	0	1
	Other	1	0	0	0	0	0	0	0	0	0	0	1

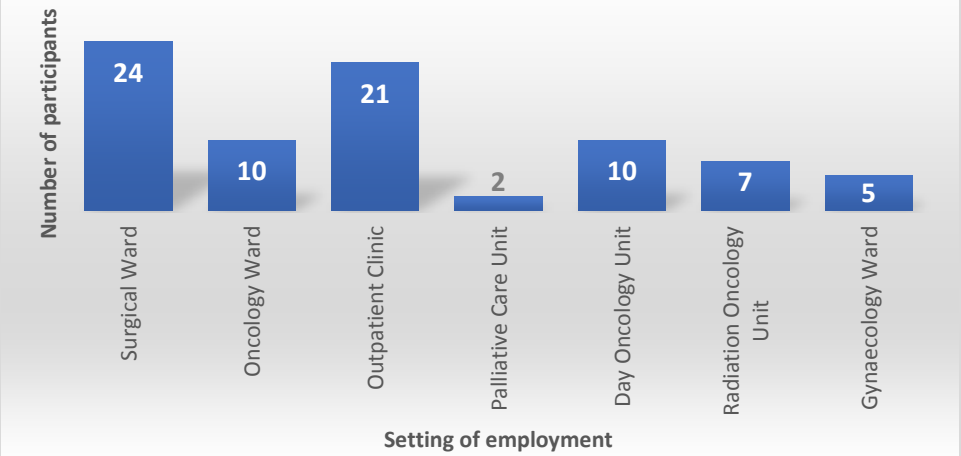
Employer / Organisation type

The majority of specialist nurse respondents (n=30) identified that they were employed at a public hospital. Of the remaining four respondents to this question three (n=3) worked at a private not-for-profit hospital and one (n=1) at a private hospital.

Setting

Specialist nurse respondents were asked to identify all settings that they work in on a regular basis. As shown in Figure 5.8, n=13 identified only one setting that they worked in on a regular basis. The remaining n=21 respondents to this question identified more than one setting. The surgical ward was identified by n= 24 specialist nurses as a setting in which they work which is in keeping with the fact that surgery is first line treatment for most gynaecological cancers. Of those, n=7 worked exclusively in the surgical ward setting.

Figure 5.8 Setting of employment (n=34)



Hours employed and job sharing

Half of the specialist nurse respondents (n=17) were employed on a full-time basis in their role. Of these, n=13 had a role that was exclusively gynaecological oncology related as shown in Table 5.7 below. It was estimated that 18 gynaecological oncology specialist nurses would be working in Australia at the time this survey was distributed. As n=20 participants indicated that their role was exclusively gynaecological oncology related, it suggests that a large proportion of the gynaecological oncology specialist nurse

populations of Australia and New Zealand responded to the survey. Participants who held a role that was not exclusively gynaecological-oncology related (n=15) were not asked to specify the proportion of their workload dedicated to caring for women with gynaecological cancers. Participants were asked if they job-shared their role. Of the n=34 responses to this question, n=3 indicated that they 'job shared' the specialist nurse role. Of these, one participant was employed for 1-8 hours per week, one was employed for 9-16 hours per week and the other was employed for 25-32 hours in the role.

Table 5.7 Hours per week and exclusivity of role

		Hours per week employed					
		1-8 Hours	**9-16 Hours**	**17-24 Hours**	**25-32 Hours**	**33-40 Hours**	**Total**
Exclusive gynaecological oncology role?	**Yes**	1	1	2	2	13	20
	No	1	2	3	5	4	15
Total		2	3	5	7	17	35

Overtime

Of the n=34 respondents to this question, n=25 reported that they worked overtime on a regular basis and n=13 of these were employed on a full-time basis as shown in Table 5.8. Twenty five (n=25) specialist nurses identified that they worked regular overtime, of which n=15 worked 1-5 hours overtime per week, and n=7 worked 6-10 hours in excess of their contracted hours as shown in Table 5.9 below. A further n=3 worked 11-15 hours per week overtime in addition to their full-time hours, the equivalent of 10-11 hour working days, five days per week.

Table 5.8 Hours per week employed and overtime.

		Hours per week employed					
		1-8 Hours	9-16 Hours	17-24 hours	25-32 Hours	33-40 Hours	Total
Regular overtime worked	**Yes**	2	2	3	5	13	25
	No	0	1	2	2	4	9
Total		2	3	5	7	17	34

Table 5.9 Hours of overtime compared with hours per week employed.

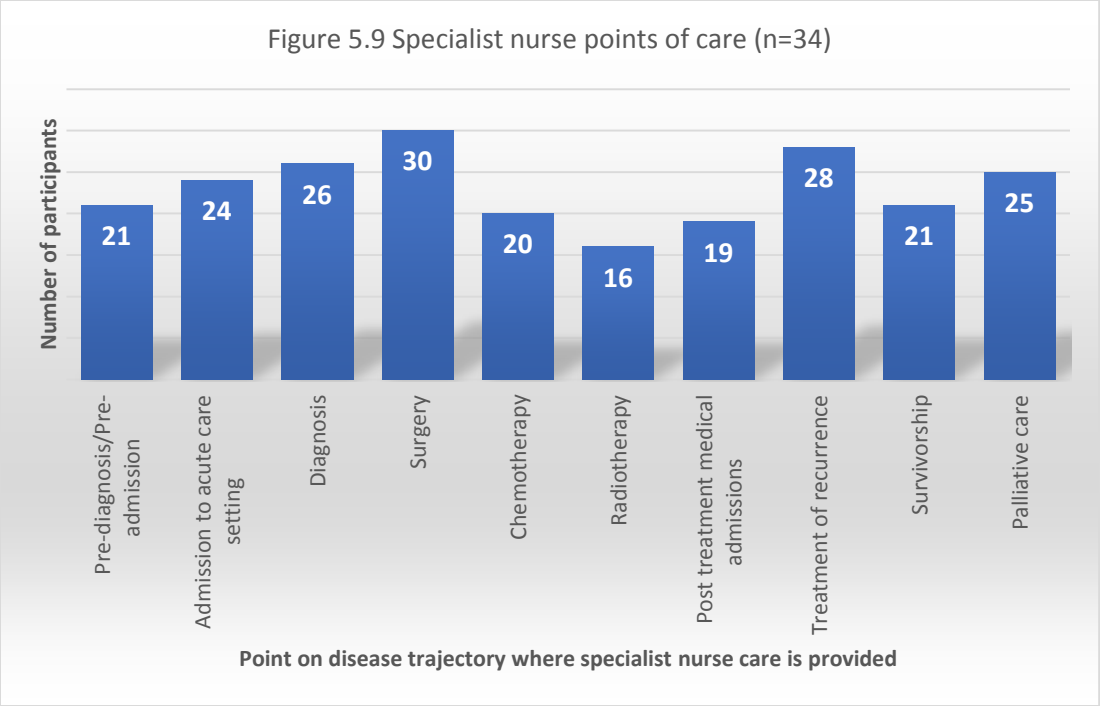
		Hours per week employed					
		1-8 Hours	9-16 Hours	17-24 hours	25-32 Hours	33-40 Hours	Total
Hours overtime worked	**1-5 Hours**	2	2	2	3	6	15
	6-10 Hours	0	0	1	2	4	7
	11-15 Hours	0	0	0	0	3	3
	Total	2	2	3	5	13	25

Scope of practice of specialist nurses

Participants identifying themselves as specialist nurses in gynaecological oncology were asked a series of questions that determined their scope of practice and at what point on the disease trajectory they provided care to women with gynaecological cancers.

Points of care

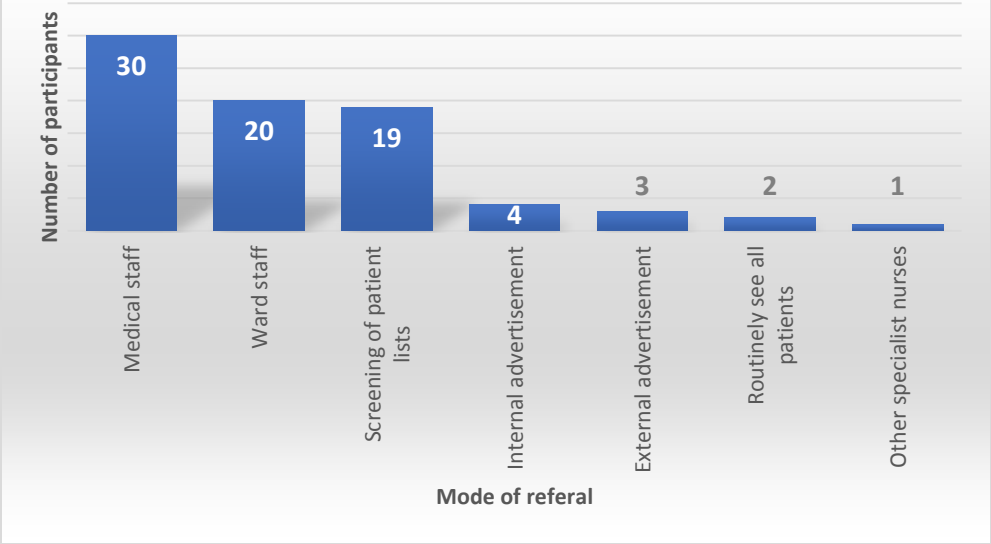
Survey respondents were asked to identify at which points on the disease trajectory they provided care to women with gynaecological cancers. The most common point of care identified by specialist nurses was at the point of surgery (n=30) as shown in Figure 5.9. The respondents who indicated they were not involved in care at this point were involved in caring for the patient whilst receiving radiotherapy and/or chemotherapy (n=4). This is commensurate with the fact that all gynaecological cancers are primarily treated with surgery. The next most common points of care were for the treatment of recurrence (n=28) indicating that the specialist nurses either maintain contact with the patient or become re-involved when recurrence is diagnosed. The point of diagnosis was also identified by the participants as a time that many specialist nurses provide care to the patient (n=26). Five (n=5) specialist nurses identified that they have contact with the patient at all stages on their disease trajectory from pre-diagnosis/pre-admission to survivorship and palliative care.



Mode of referral

The most common mode of referral to the specialist nurse was from medical staff (n=30). This was also the only identified source of referral for nine (n=9) specialist nurses indicating that in those cases it was medical professionals deciding which patients will receive care from the specialist nurse. The next most common sources of referral were from ward staff (n=20) and through the screening of patient lists and (n=19). Figure 5.10 shows the number of participants who identified each referral sources as applicable to their service.

Figure 5.10 Mode of referral to specialist nurse (n=34)



Caring for 'external' patients.

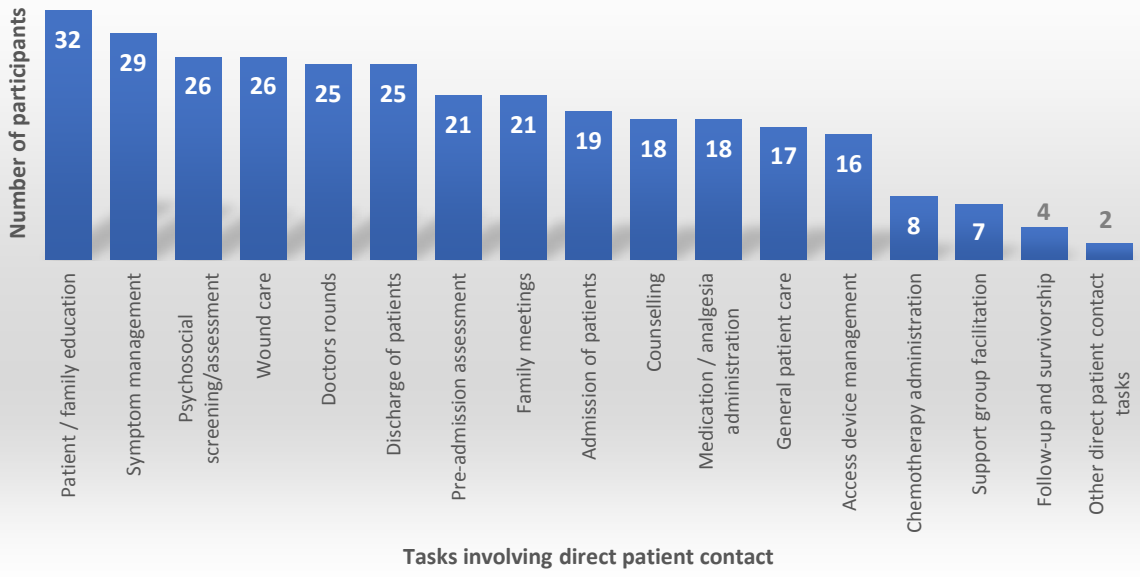
This section of the survey asked specialist nurse participants if they provided care for women who were not patients of their service. Twelve (n=12) specialist nurses reported that they also cared for women who were not patients of their service. Five (n=5) identified that their employer funded this with patients either referring themselves to the service (n=1) or other hospitals referring patients to the specialist nurse (n=3). Two (n=2) specialist nurses identified that they provided care or advice to external patients 'under the radar' (when specialist nurses see external patients unbeknown to their employer) or without funding from their employer. Other specialist nurses identified that external patients contacted them (n=3) but did not indicate how this was funded.

Tasks involving direct patient contact

Specialist nurse participants were asked to identify tasks completed on a regular basis that involved direct patient contact as shown in Figure 5.10. The six most commonly performed tasks involving direct patient

contact were education of the patient and family (n=32, 94.1 per cent), symptom management (n=29, 85.3 per cent), psychosocial screening/assessment (n=26, 76.5 per cent), wound care (n=26, 76.5 per cent), doctors rounds (n=25, 73.5 per cent), and discharge of patients (n=25, 73.5 per cent).

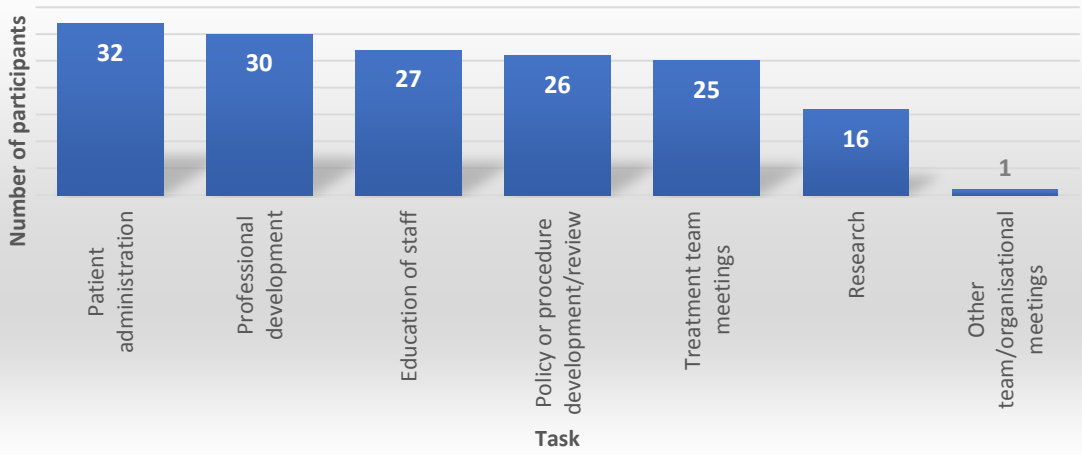
Figure 5.11 Direct patient contact tasks (n=34)



Tasks not involving direct patient contact

Participants identifying themselves as specialist nurses were also asked to identify all tasks that did not involve direct contact with the patient that they completed on a regular basis. Almost all respondents (n=32, 94.1 per cent) identified that they completed administration tasks related to the patient's care such as making appointments and referral to other service. Figure 5.12 Refers to the tasks completed by specialist nurse that do not involve direct contact with patients.

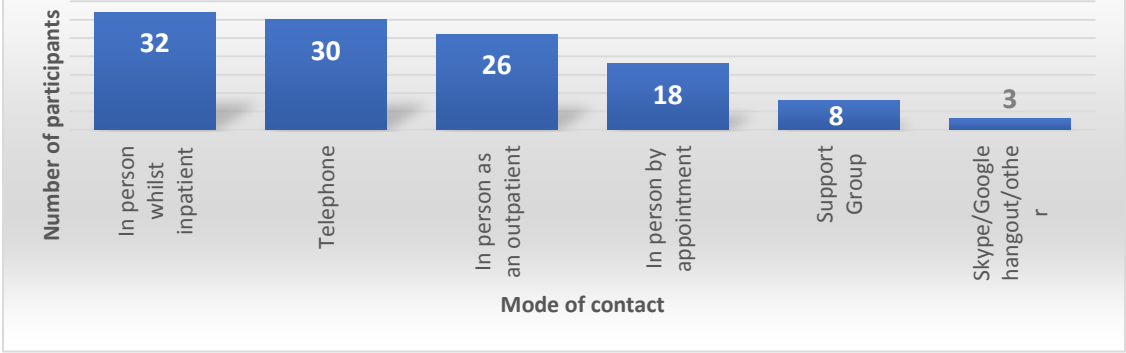
Figure 5.12 Tasks without direct patient contact (n=34)



Mode of contact

Specialist nurse participants (n=34) were asked to specify the modes through which they have contact with their patients. The most common form of contact with patients was in-person whilst the patient was an inpatient in hospital (n=32). For two (n=2) participants this was the only mode of contact they had with the patient. Telephone contact was utilised by n=30 participants in the care of their patients. Many participants also had contact with their patients as outpatients (n=26). Most specialist nurses identified multiple modes of contact with the patient though only one specialist nurse (n=1) identified that they utilised all six modes listed in Figure 5.13 below.

Figure 5.13 Mode of contact with patients (n= 34)



Outpatient consultations

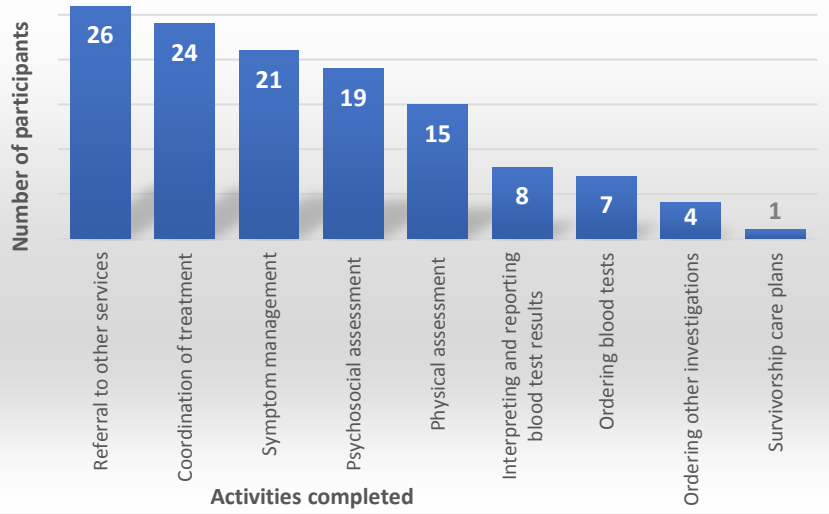
The specialist nurses involved in outpatient consultations were asked to identify, from five options, the one that best suited the type of outpatient consultation that they engaged in. Participants were able to select more than one option. Of the participants who answered this question (n=29), some selected only one option (n=12) and all others indicated that their outpatient consultations with patients were conducted in more than one format (n=17). The most common format selected was where the medical specialist and specialist nurse conducted the consultation together (n=18). No participants selected the option where the specialist nurse consults with the patient independent of the medical specialist but follows a procedure regarding the timing and content of the consultation. There were however seven (n=7) specialist nurses who identified that they were conducting nurse-led clinics that were an alternative to follow-up with a medical specialist. Table 5. 10 shows the format of outpatient consultations that specialist nurses were involved in.

Table 5.10 Format of outpatient consultations n=29

Consultation is conducted by medical specialist and SN together	Medical specialist and SN consultations are conducted separately on same day	SN consultations are independent of medical specialist consultation according to procedure	SN consultations are independent of medical specialist consultation according to patient need	SN consultations are an alternative to follow-up with the medical specialist ie a nurse-led follow-up clinic.
18	14	0	14	7

Specialist nurses were also asked to select all relevant activities, from a list provided, that they completed during the outpatient consultations. Of the twenty-six respondents to this question, all of them stated that they referred patients to other services during their outpatient consultation as shown in Figure 5.14. Coordination of care (n=24) and symptom management (n=21) were the next most common tasks completed by specialist nurses during outpatient clinics.

Figure 5.14 Activities completed in outpatient consultations n=26



Nurse-led clinics

As indicated in the question regarding outpatient clinics, seven (n=7) specialist nurses identified that they conduct nurse-led clinics as an alternative for the woman to being seen by a medical specialist. The specialist nurses were asked to describe the details of their clinic including the cancer type and stage affecting the women attending the clinic, along with a basic outline of their protocol. A content analysis was conducted where coding of the responses found that one (n=1) of the specialist nurses ran a nurse-led clinic for her breast cancer patients only and the other six (n=6) ran clinics for women with gynaecological cancers. These clinics had different foci – four (n=4) were termed 'follow-up clinics', one (n=1) was a pre-admission clinic and the other a survivorship clinic (n=1). Five (n=5) specialist nurses indicated that they treated women with early stage endometrial cancer, two (n=2) treated women with early stage cervical cancer and one (n=1) clinic treated women with borderline ovarian cancer. The patients with borderline ovarian cancer were two years post treatment (bilateral salpingo-oopherectomy) and elected to attend the nurse-led clinic.

Other aspects of role

Specialist nurse participants in the survey were given the opportunity to identify any other aspects of their role that they felt had not been addressed by the survey. The twenty-one (n=21) responses received were coded and it was found that four (n=4) nurses identified complex care coordination as an aspect of their role not covered by the survey. Table 5.11 shows the number of participants identifying other aspects of their role not covered by the survey and the frequency with which each was identified.

Table 5.11 Other aspects of specialist nurse role not covered by survey n=21

Aspect of role	**n**
Complex care coordination	4
Preparation of cases for MDT	2
Attendance at other organisational meetings	2
Networking/Awareness of other specialist nurse	1
Triage of new patients	1
Continuity of care provided by SN	1
Pre-admission consultation	1
Clinical expert on ward	1
Theatre bookings and list management	1
Fill in for leave on ward	1
Development of nurse-led clinic	1
Teaching	1
Hybrid nursing roles	1
Other	1

This section of the chapter described the specialist nurses who responded to this survey and 'what' they do in caring for women with gynaecological cancers. Among the survey participants, the earliest the specialist nurse role emerged was 1987 in Australia and 1999 in New Zealand. On average the specialist nurses who responded to this survey were very experienced nurses who had held their position for several years. Most had post-graduate qualifications, with over a third holding a master's degree and had tailored their education to their role by completing various other short courses. Unlike New Zealand where all specialist nurses held the same role title, Australian specialist nurses held varying role titles between and within states and territories. With the differences in role titles there were also differences in reporting lines and not all participants held gynaecological oncology exclusive roles. Participants were not asked to provide their pay scale hence it is not known if the difference in role titles and reporting lines translated to a different pay scale. Employment conditions were varied with participants employed in a gynaecological oncology specialist nurse role between one and five days per week. Regardless of this, the majority of specialist nurses worked regular overtime.

The care provided by the specialist nurses who participated in the survey traversed settings, with 62 per cent stating that they worked in more than one setting. The most common points on the disease trajectory of women with gynaecological cancers for specialist nurses to be involved were at the point of surgery and disease recurrence. Patient and family education and symptom management were the most commonly identified tasks completed by specialist nurses that involved direct contact with the patient. Patient administration including booking appointments and making referrals were the most common tasks performed by specialist nurses not requiring direct contact with the patient. Participants most commonly identified that women were referred to their service by medical staff and some specialist

nurses cared for women outside of their service. Various modes of contact between the specialist nurses and women were used including inpatient and outpatient consultation, telephone, support groups and Skype. Specialist nurses who were involved in outpatient consultations were involved in different ways ranging from attendance alongside the medical specialist to conducting nurse-led clinics.

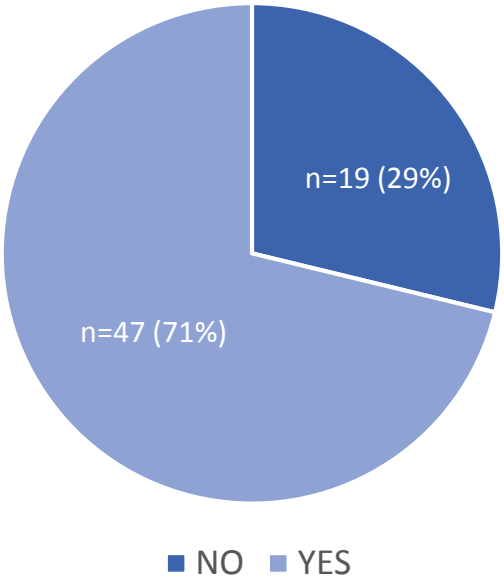
The perspectives of gynaecological oncology treatment team members

This section of Chapter 5 presents the survey responses of participants who identified themselves as members of gynaecological oncology treatment teams, other than specialist nurses. Treatment team members responded to questions relating to their experiences and perceptions of the specialist nurse role. Within the survey, treatment team members responded to a mixture of closed and open-ended questions. The responses to closed-ended questions were analysed using SPSS v.23 and Microsoft Excel 2013. The responses to open-ended questions were subjected to a content analysis within NVivo Pro V.11. Overall n=67 participants identified themselves as members of gynaecological oncology treatment teams other than specialist nurses, however not all participants answered all questions and the sample size for each question is reported.

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 n=66 treatment team members who responded to this question, n=47 did have a specialist nurse working within their team and n=19 did not as depicted in Figure 5.15.

Figure 5.15 Specialist nurse in team n=66



Frequency of contact with the specialist nurse

Participants who stated that there was a specialist nurse employed in their team (n= 47) were asked to identify how often they had contact with the specialist nurse. More than half of the participants (n=24, 51.1 per cent) who responded to this question indicated that they had daily contact with the specialist nurse in their team. The next most common frequency of contact was once per week, identified by n= 13 (27.7 per cent) participants. Table 5.12 below indicates the frequency with which team members had contact with their specialist nurse.

Table 5.12 Team members' frequency of contact with specialist nurse n=47

		Role in team												
		Nurse Practitioner	Cancer Service Coordinator	Nurse Educator	Registered Nurse	Gynae-Oncologist / Fellow/Registrar	Gynaecologist / Registrar/Fellow	Medical Oncologist / Registrar/Fellow	Radiation Oncologist	Social Worker	Dietician	Psychologist	Research-related role	**Total**
Frequency of contact with the specialist nurse	Daily	2	2	1	2	6	2	4	1	1	0	2	1	**24**
	2-3 times week	0	0	0	0	1	0	1	0	0	0	0	0	**2**
	Weekly	0	2	0	1	0	0	4	2	0	1	1	2	**13**
	Fortnightly	0	0	1	0	0	0	0	0	0	0	0	0	**1**
	Monthly	0	0	0	0	0	1	0	0	0	0	0	0	**1**
	As required	0	1	0	1	0	0	0	0	0	0	0	0	**2**
	Other	0	2	0	1	0	0	0	0	0	0	0	1	**4**
Total		**2**	**7**	**2**	**5**	**7**	**3**	**9**	**3**	**1**	**1**	**3**	**4**	**47**

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

Participants identifying themselves as members of a treatment team which included a specialist nurse were asked to identify what they thought were the key aspects of the specialist nurse role. A total of n = 44 responses were recorded and responses were coded to minor categories from which five main categories were derived – Communication, navigation and coordination; Required knowledge, skills,

attributes and experience; Contact, support and advocacy; Education and information provision; and Assessment, management and referral. Responses were coded to one or multiple minor categories depending on the complexity of the response. Table 5.13 shows the five main categories, the minor categories from which they were derived and corresponding participant responses.

Table 5.13 Key aspects of specialist nurse role identified by treatment team members n=44

Major Category	Minor category (n)	Participant examples
Communication, navigation and coordination	Coordination of care (22)	*"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 one patient support groups"* – *Medical oncologist* *"To coordinate the trajectory of women through diagnosis and management of gyn[aecological] malignancy."* – Radiation oncologist *"Ensuring follow up of issues, problems and results"* – Gynaecological oncologist *"She is a central person within the gynaecological oncology team and facilitates patient care throughout the experience. This is especially important as she is involved from the pre-surgery point."* - Psychologist *"Total management of patient care including care coordination, triaging, wound care, ward management and follow-up."* – Gynaecological oncologist *"In my experience the specialist nurse coordinates the patients care, ensuring that the patient is seeing the doctor and all the other health professionals they may require, and everything is happening smoothly."* – RN and research assistant *"An essential part to the coordination of gynaecology oncology patient care"* – Gynaecologist
	Communication and	*"Our nurse is the glue for our team"* – Medical oncologist

	Liaison (21)	*"Link between primary and secondary care"* – Gynaecological oncologist *"Communication with patients and doctors re treatment, results, surgery etc"* – Dietician *"Liaises with women, their families and other care providers"* – RN (Ward) *"Ability to liaise between 'Patient land' and 'Dr land'"* - Psychologist *"In particular to provide a link between the subspecialties, where several specialists are involved in care (which is frequently the case with gynae cancer pts)."* – Medical oncologist *"Often crucial in explaining and de-medicalising the situation for the patient"* – RN and research assistant
	Navigation and system knowledge (8)	*"Navigator for the patient at all points in the journey."* – Gynaecological oncologist *"Maintain, support and organisation of the team as a whole with focus on the patient's experience navigating through the process and advocating for them."* – Gynaecology registrar *"Providing a link into a complex network"* – Medical oncologist *"System knowledge - how to get things done quick"* – Nurse practitioner *"Liasing with outpatients who have to attend 3 different centres for treatment"* – RN (ward)
Required knowledge, skills, attributes and experience	General skills and attributes (20)	*"Empathy"* – Cancer care coordinator *"Respectful of all team members contributions to patient care"* - Psychologist *"Self directed"* – Cancer care coordinator *"Willingness/ability to stay up to date with treatments and disease info"* – Cancer care coordinator *"Approachable"* - Researcher *"Expert communication skills"* – Nurse Practitioner

	"Ability to provide information at pts level of understanding" – Cancer Service Coordinator *"Skills in having difficult conversations"* – Cancer service coordinator
Gynaecological oncology specialist (17)	*"Expertise in fertility/sexuality issues"* – Gynaecological oncologist *"-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 including endocrine, sexual counselling, allied health, palliative and symptomatic care , MSW etc."* – Radiation oncologist *"Providing specialist-nursing advice especially in regarding the sexual health and supportive care during treatments"* – Radiation oncologist *"Provision of nurse led follow up clinic"* – Psychologist *"Expert knowledge in the various gynaecological cancer diagnoses: aetiology, surgical management, adjuvant treatments and side-effects of treatments. Good understanding of the impact of the diagnosis and treatment on patients and families: prognosis, work implications, treatment duration, psychosocial and psychosexual issues, particular needs of regional/remote patients, Indigenous patients and CALD women"* – Social worker
Multi-disciplinary team (4)	*"Brings wholistic approach to MDT team"* – Clinical research nurse / Study Coordinator *"Leadership within the multidisciplinary team"* - Gynaecologist *"Active participant in MDT meetings"* – Social worker
Research (4)	*"Identifying potential patients for clinical trials."* - Researcher *"Promotes research to add to the evidence or to identify gaps in service eg patient unmet needs, health professionals*

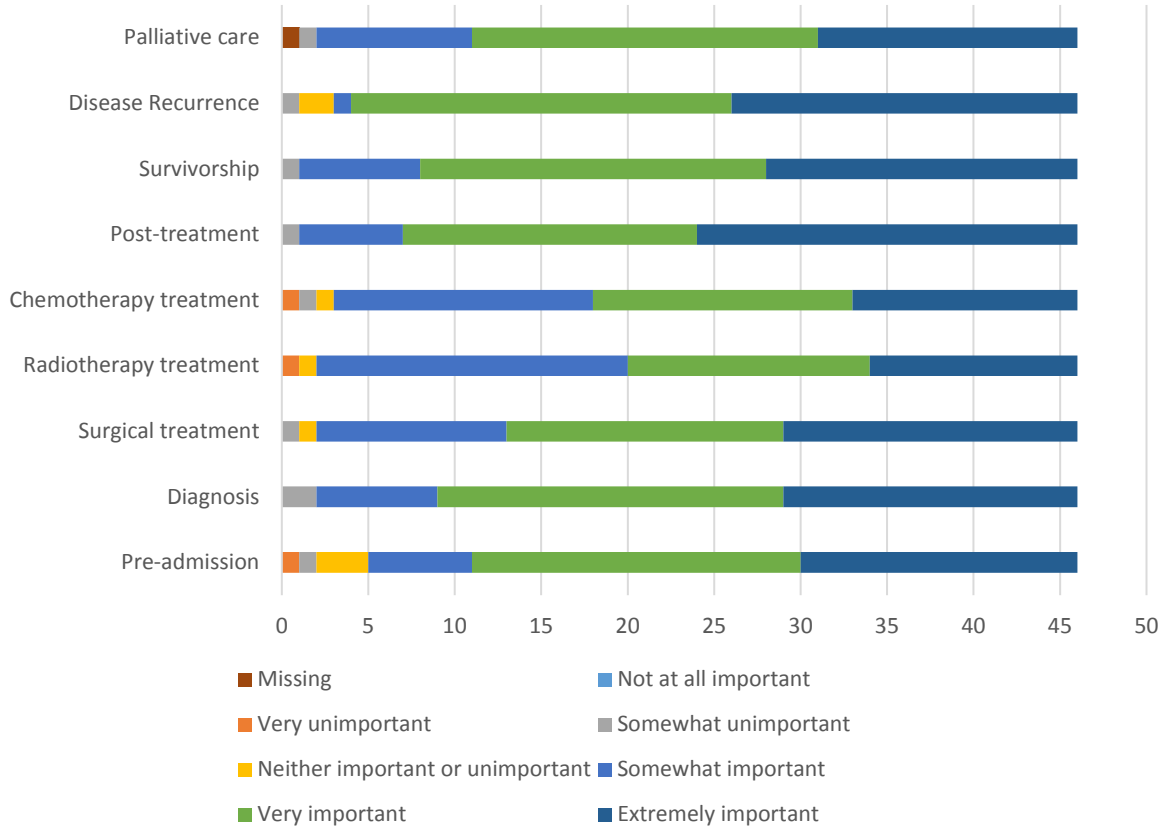
		adequately supported" – Cancer service coordinator *"Research involvement where appropriate"* – Social worker
Contact, support and advocacy	Patient support and advocacy (19)	*"… to provide general support for patients struggling for whatever reason eg emotionally, physically"* – Medical oncologist *"She is an important anchor person for the patient and available to assist with questions. She is a go between with the patient and consultant team in the public health system, to advocate for the patient."* – Nurse educator *"Extra time for the patient* – RN (chemotherapy) *"Helping with financial/social/physical turmoil of a cancer diagnosis"* – RN (chemotherapy) *"Supporting the patient and their family through their experience"* – Gynaecology registrar *"Ensuring patients are aware of resources available to them"* – Radiation oncologist
	Key contact (13)	*"Direct point of communication for patient"* – Medical oncologist *"Single point of contact for patient and clinicians"* – Gynaecological oncologist *"She is a central person within the gynaecological oncology team and facilitates patient care throughout the experience."* - Psychologist *"First and ongoing point of contact for the patient from initial visit to the outpatient clinic through hospital treatment and following discharge through the process of follow up and ongoing treatment after surgery."* – Nurse educator *"They are a consistent point of contact for the patient"* – RN and research assistant *Point of contact for women following discharge who have concerns about their recovery* – Social worker
	Patient and family education and information provision	*"Reduction in anxiety by provision of information"* – Gynaecological oncologist

Education and information provision	(14)	*"Education of patients and their families, physical and psychological preparation of patients and their families for treatment."* – Nurse educator *"Disease specific information. Information about the treatment options and the pro and cons of choices"* – Cancer service coordinator *"Information about treatment, side effects and post treatment care"* – Radiation oncologist
	Staff professional development (10)	*"Education for nurses and other staff"* - Dietician *"Use opportunities to share knowledge with less experienced staff"* – Cancer care coordinator *"Educate fellow nurses"* – Gynaecological oncologist *"Educator and Mentor for other health care professionals"* – Cancer service coordinator *"Education of nursing staff and other disciplines"* – Social worker
Assessment, management and referral	Assessment and referral (11)	*"Making appropriate referrals to allied health professionals including social work and palliative care teams"* – Radiation oncologist *"Assessment and identification of care priorities and providing appropriate referrals"* – Nurse educator *"They meet unmet needs or at least initiate that process"* – RN and research assistant *"Support and triage about psycho-social concerns"* - Psychologist
	Symptom, side-effect and complication management (5)	*"Management, in consultation with surgeon, of minor post-operative complications, eg minor wound issues, constipation, minor infections. Treating of patients post op problems, eg see GP, see surgeon, reassurance and see no one."* – Gynaecological oncologist *"Detect ongoing toxicities"* – Medical oncologist

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

Treatment team members were asked to rank the importance of the involvement of a specialist nurse in the care of women at given points on their disease trajectory. Of the total n=46 participants who responded to this question, n= 35 (76.2 per cent) identified that it was 'extremely important' or 'very important' that specialist nurses were involved in women's care prior to admission. Likewise, n=37 (80.5 per cent) of participants with a specialist nurse in their team thought that it was 'extremely' or 'very' important that a specialist nurse be involved at the point of diagnosis of the cancer. Although n=33 (71.8 per cent) thought that surgical treatment was an 'extremely' or 'very' important stage for specialist nurse involvement, n=11 (23.9 per cent) did think that this was 'somewhat important'. This compares with the stages of chemotherapy and radiotherapy treatment where more than one third of participants, n= 15 (32.6 per cent) and n= 18 (39.1 per cent) respectively, believed that specialist nurse involvement was 'somewhat important'. Figures 5.16 shows the levels of importance attributed by treatment team members to specialist nurse involvement at various stages along the disease trajectory.

Figure 5.16 Treatment team importance of involvement of SN along disease trajectory



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 (n=38) participants responded to this question with n=16 (42 per cent) 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. Table 5.14 provides a summary of treatment team experiences in relation to role overlap with their specialist nurse.

Table 5.14 Treatment team experiences of role overlap with their specialist nurse

Category (n)	Participant examples
Role Overlap exists (8)	*"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 *"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 *"Yes, usually to source resources/ appropriate referral pathways"* – RN (ward) *"There definitely is an overlap but the roles combine very efficiently I have never had a problem here."* – Gynaecological oncologist *"I think the role overlap compliments our role as physician as she coordinates things with a very patient centred approach"* – Medical oncologist
Strategies to manage role overlap (15)	*"Defining roles and rediscussing responsibility framework when this happens.* *Clear job description."* – Gynaecological oncologist *"Good communication ensures there is not duplication of work"* – Gynaecological oncologist *"We work together as a team. I am lucky as I have previously relieved in her role so have some idea of the role and it is essential to communicate with each other and to identify who is doing what if there is an overlap."* – Cancer care coordinator *"We work together, both having a patient focus means we know we are working for the same aims and goals, we recognise our strength exists in our differences working together as a team not separately as individuals"* - Psychologist *"We have established role boundaries between my role as Cancer Nurse Coordinator and hospital-based specialist nurse. We meet periodically to review role boundaries and address any new concerns. If there was a role overlap, we would negotiate who does what - there is sufficient work to keep us all busy"* – Cancer nurse coordinator *"Yes...she is the gynaecological CNC and I am the rural CNC so when caring*

	for rural patients it is a matter of negotiating who will do what for the patient and who will provide the support at the different stages. This is usually a very successful division of roles, however sometimes there is double up of work if the patient has contacted us both for the same issue. This can lead to frustration at times. Good communication is vital." – Cancer service coordinator *"Share an office so we talk and share - I help them - they help me – pt [patient] benefits"* – Nurse practitioner *"Clear communication and respect of each others' roles prevents issues arising about role overlap. In terms of information provision, there will always be some areas of overlap, but this doesn't become a problem when each "specialist" is clear about the limits of their skills and responsibilities. Comprehensive understanding of the specific roles of each discipline can work to the advantage of patients. In the absence of one of the team members (eg, when on leave) the availability of someone to give basic information and make a plan for appropriate follow up is an example of where so-called "role overlap" is helpful. Role overlap only becomes a problem where there is lack of respect by one party about the skills or experience of others."* – Social worker
Other comments in relation to role overlap (7)	*"Much of what is now done by the CNC that works with me used to be done by the gynae oncology fellow. Having recognition for this role by the hospital beds this down as part of standard of care."* – Gynaecological oncologist *"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 with other specialists. If she didn't help, then more would fall to me to do."* – Medical oncologist *"She is capable of giving the chemo toxicity discussion, though I still normally do this myself as well."* – Medical oncologist *"The role is not clearly defined in my institution and inpatients are often neglected."* – RN (ward)

Benefits and disadvantages to *women* with gynaecological cancers of the specialist nurse role as identified by treatment team members

Of the n= 47 treatment team participants who identified that they worked with a specialist nurse, n= 44 identified what they perceived as the benefits and disadvantages to women with gynaecological cancers

of having a specialist nurse involved in their care. Table 5.15 represents the benefits and disadvantages identified by treatment team members to women of receiving care from a specialist nurse. Participant responses were coded and then aggregated into categories based on similar meaning. Table 5.15 provides examples of participant responses according to the subject they relate to. The majority of responses were positive towards the specialist nurse role and n = 18 stated explicitly that they saw no disadvantage in the involvement of specialist nurses in gynaecological cancer patients' care. Nine (n= 9) participants identified disadvantages to the specialist nurse role relating mainly to dependence of the patient and team members on their care and the workload and self-care needs of specialist nurses.

Table 5.15 Treatment team members perceived benefits of specialist nursing care to women with gynaecological cancers

Major category	**Minor Category**	**Participant examples**
Communication, coordination, continuity.	Point of contact (18)	*"The patients regard her as the most important person on our team"* – Gynaecological oncologist *"Someone to connect with at any time they feel they need to talk"* – Nurse educator *"Clear point of contact, making it easier to manoeuvre through often complex multidisciplinary care"* – Medical oncologist *"Designated person for communication"* – Dietician *"Availability. More time to spend with patient and potentially better access"* – Gynaecological oncologist
	Continuity of care (9)	*"All benefits really – the continuity of care is central to this role as the woman sees a number of health professionals"* – Radiation oncologist *"Offers continuity of care throughout the patient journey"* – Cancer service coordinator *"Follow up"* – Gynaecology registrar

	Coordination of care and navigation of system (8)	*"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 *"Signposting where to go and what to do to navigate the health minefield"* – Cancer service coordinator *"Clear coordination of care"* – Medical oncologist
	Assessment and referral (8)	*"Holistic and comprehensive psychosocial assessment and referrals"* – Nurse educator *"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 *"Facilitating access to members of the treatment team who are best placed to assist with issues arising for the woman; particularly those issues that arise post-acute surgical discharge."* – Social worker *"Being able to link patient in with other services"* – Nurse practitioner
Source of knowledge and information	Expertise (18)	"*Advanced level of knowledge"* – RN – ward *"The benefits to women are they can develop of patient-nurse relationship with one person who is an expert in their field"* – Gynaecologist *"Expert knowledge gained from a "critical mass" of experience with women who have gynaecological cancer"* – Social worker *"The ability to easily contact and seek information, support and care from an experienced specialist nurse is extremely beneficial for the women.* – Psychologist
	Education and Information provision (14)	*"A source of trustworthy and evidence based information, education and support"* – Nurse educator *"Someone who has time to answer questions and clarify the doctor speak & demystify the jargon"* – Cancer service coordinator *"Get the appropriate education tailored to their needs and*

		their own diagnosis" – Cancer service coordinator *"Accurate provision of information"* – RN –ward *"I think the one on one time they get is invaluable for them, especially the education"* – RN – chemotherapy
Holistic care	Patient support and advocacy (18)	*"Ongoing support as required especially at times when at risk of high stress e.g. diagnosis, referral to other treatments (chemotherapy +/- radiotherapy) recurrence, referral to palliative care"* – Cancer service coordinator *"Patient advocate – at consultations, within the service and at strategic management level"* – Cancer service coordinator *"Psychosocial support leads to calmer, more settled and relaxed patients"* – Cancer service coordinator *"Our doctors can be very good at prescribing and operating. But they're particularly not good at acknowledging, treating and preventing side effects, especially things like scar tissue or loss of sensation with vulvectomies for example. The specialist nurse becomes an advocate for the patient in this area – either providing information or access to support services. I think that's invaluable to our women"* – RN and research assistant
	Therapeutic relationship (12)	*"It has clear psychological benefit for the women to have such a relationship with a nurse that they trust and respect"* – Psychologist *"The woman is more likely to feel confident to discuss various aspects of her condition and treatment that she may otherwise be reluctant to discuss."* – Nurse educator *"Patients in my experience often share some of their more personal concerns and worries about treatment and their cancer journey with the gynaecology oncology nurse."* – Gynaecologist *"More time to spend with pt"* – Medical oncologist *"I have found patients develop a strong relationship with them"* – Gynaecologist

	Improved patient care and outcomes (11)	*"Focus on good symptom control and monitoring of longer term toxicities"* – Medical oncologist *"I think they play a key role in improving patient outcomes and delivery of care."* – Medical oncologist *"Individualised attention"* – Medical oncologist *"Better nursing care overall"* – Dietician
Disadvantages	Dependence (3)	*"Can take on too much responsibility. Can become more important than the role. Allows other team members to not fulfil their roles."* – Gynaecological oncologist *"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 *"The patients can become dependent and not take responsibility for themselves".* – Medical oncologist
	Workload and self-care (2)	*"I think there is a risk that they take on too much however"* – Medical oncologist *"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

Benefits and disadvantages to *patient's families* of the specialist nurse role as identified by treatment team members

Survey participants who identified themselves as treatment team members were also asked to provide their perceptions of the benefits and disadvantages of the specialist nurse to patient's families. A total of n=44 participants responded to this question though n=18 referred directly back to their response to the question relating to the benefits and disadvantages of the role to the patient themselves indicating that they saw the same benefits to family members as to the patient. Likewise, the categories of responses provided by the remaining participants also echoed those relating to the benefits and disadvantages to

women of the specialist nurse role. Responses were coded to minor categories which were the arranged into three major categories: Communication, coordination and continuity; Support and advocacy; and Disadvantages. Table 5.16 depicts the major categories and the minor categories and participant illustrations from which they were derived.

Table 5.16 Benefits and disadvantages to patient's families of the specialist nurse role as identified by treatment team members.

Major category	Minor Category (n)	Participant examples
Communication, coordination and continuity	Contact person (9)	*"Families have one known source that they know they can seek for support and information. Ward nurses come and go they are not a constant every day. The Specialist nurse is the one easily accessible person that they see every day while the woman is in hospital (Monday to Friday)."* – RN (ward) *"They have a constant single point of contact"* – Gynaecological oncologist *"A point of contact in a complicated health care system"* – Radiation oncologist *"Additional and more easily accessible medical team member- able to offer medical and social support"* – Medical oncologist
	Assessment and referral (7)	*"…appropriate referrals to support services eg Canteen."* – Radiation oncologist *"Ensure patient is referred to all required services to reduce the burden of responsibility on family members"* – Cancer service coordinator *"Offer resources to help with the cancer journey. Know how to access services for both patient and family"* - Gynaecologist *"The specialist nurse can refer the family to appropriate services for whatever assistance they require"* – Nurse

		educator
	Coordination (6)	*"Support in navigating the treatment pathway"* – Cancer service coordinator *"Provide point of contact to co-ordinate care"* - Gynaecologist *"Coordination of care to ease transport, childcare etc concerns."* – RN and research assistant
	Continuity (3)	*"Offers continuity of care throughout the patient journey, a 'go to' person to support family members and reduce the burden of responsibility which can be overwhelming."* – Cancer service coordinator
	Communication (3)	*"Communication and repeating the information the patient receives during the consultations at hospital"* – Radiation oncologist
Source of knowledge, support and advocacy	Ongoing support (19)	*"Increased emotional support, supportive assistance between appointments"* – Medical oncologist *"More time with patient and/or families"* – Dietician *"An additional support person"* – Radiation oncologist *"Someone to phone if need advice on how to support someone with gynaecological cancer."* - Researcher *"Supports family members as well as the patient to reduce their stress"* – Cancer service coordinator *"Reassurance and support that everyone is acknowledged and heard"* – RN and research assistant *"Acknowledgment of the stresses of being a carer and their unique needs"* – Social worker
	Education and information (10)	*"Someone who can explain/educate issues relating to gynaecological cancer"* - Dietician *"Access to high level of knowledge"* – Gynaecological oncology fellow *"Point of contact, someone to explain more clearly to family members if patient consents - the diagnosis and tmt plan."* – Cancer service coordinator *"Communication and repeating the information the patient*

		receives during the consultations at hospital" – Radiation oncologist *"Provision of information about the specific needs of caregivers."* Social worker
	Advocacy (2)	*"Patient & family advocate - at consultations - ensures they understand what is said and can repeat if patient consents to family member who was unable to attend"* – Cancer service coordinator *"Advocate within the service and at strategic management level to ensure family members needs are met"* – Cancer service coordinator
Disadvantages	Disadvantages (2)	*"CNCs are already busy so don't always have extra time for relatives as well as patients."* - Researcher *"Sometimes they feel that only the specialist nurse can help whilst often the ward staff have more experience/knowledge"* – RN (ward)

Benefits and disadvantages to the treatment team of the specialist nurse role as identified by treatment team members

Participants identifying themselves as members of the treatment team were asked to state what they perceived to be the benefits and disadvantages of the specialist nurse role to the team. Forty-three (n= 43) participants responded to this question with one participant identifying a disadvantage related to the personal burden of the role on the specialist nurse as illustrated in Table 5.17 below. Overall the responses to this question indicated that the specialist nurse role assisted other members of the treatment team. Responses were coded to minor categories and then aggregated into five major categories: Team leadership, support and coordination; Assistant; Patient-focussed care; General benefits; and Disadvantages. Table 5.17 depicts the five major categories, the minor categories from which they were derived (with frequency of responses) and participant illustrations.

Table 5.17 Benefits and disadvantages of the specialist nurse role to the treatment team as perceived by treatment team members.

Major category	Minor Category (n)	Participant examples
Team leadership, support and coordination	Continuity, communication and coordination (24)	*"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 *"Significant. 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 *"Coordination of care between medical members in different parts of [name of state]"* – Medical oncologist *"They liaise between ward staff and specialist team as well as allied health and community services to keep everyone up to date"* – Nurse educator *"Brings solidarity, care coordination and continuity of care particularly back to the rural area where the patient lives as the specialist nurse is usually in the Metro area"* – Cancer service coordinator *"Smoother work flow"* – Radiation oncologist *"Huge benefits to the team from organisation and follow up to discharge planning and support networks"* – Gynaecology registrar
	Leadership and support within team (9)	*"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 *"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 *"Contributing to a sense of support and cohesion within the team to enhance the development of trusting relationships and promote emotional well-being of all team members."* – Social

		worker *"Provide support to patient and team members during difficult consultations"* – Gynaecologist *"We would be lost without our specialist nurses. They are incredibly valuable resource to both patients and other team members."* – Gynaecological oncology fellow
Assistant	Lighten the load (8)	*"Able to take over some aspects of care from medical team"* – Radiation oncologist *"The CNS/CNC has more time to spend with the patient to explain things - which makes the doctors jobs easier; the CNS/CNC can do the coordination required for patient appointments on behalf of the team making their jobs easier"* – Cancer service coordinator *"It gives them an extra person to lighten the load when it comes to explaining, education etc"* – RN (chemotherapy) *"I think the specialist nurse is a safety net for the doctors. Where they forget or neglect holistic care, the specialist nurse steps in. A lot of nurses will turn to the specialist nurse with 'minor' concerns rather than bother a doctor."* – RN and research assistant *"Delegation of communication and co-ordination tasks"* – Medical oncologist
	More time (7)	*"Specialist nurses can manage many of the simple issues that may arise, thus freeing up time for the members of the treating team."* – Gynaecological oncologist *"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 *"Have more time to spend with patients and can feedback information to the team which may otherwise have not been obtained"* – Gynaecologist *"Potentially able to spend more time with patient and have time to be a resource for them - take the load."* – Cancer service coordinator
	Reliability and consistency (7)	*"Trust the patient will have the agreed and recommended tests/treatments."* – Radiation oncologist *"There is a huge base of experience and knowledge available*

		even when the Drs aren't there" - Psychologist *"Reliable follow-up of symptoms in between medical appointments"* – Medical oncologist *"Dissemination of information - consistent information delivery"* – RN (ward)
	Ongoing patient support (6)	*"Increased support during/ between appointments."* – Medical oncologist *"Good support for patient so is of benefit to entire treatment team"* – Medical oncologist *"Survivorship better addressed by nurse"* – Gynaecological oncologist
	Additional education and information (3)	*"Through continuity of care the nurse is able to develop rapport with the woman and provide information and education to ensure that the woman is fully informed and has understanding of her treatment choices before consenting. The provision of trusted information and education ensures that the woman understands the importance of follow up treatment and care for ongoing monitoring of disease."* – Nurse Educator
Holistic care	Offers the patient's perspective (10)	*"Different perspective - hearing the patient voice more"* – Medical oncologist *"The specialist nurse has a significant contribution and 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 *"Broad oversight, advocate for women and the families."* – RN (ward) *"They can inform the team of patient circumstances that my impact on receiving treatment."* – Nurse Educator
	Patient-centred (6)	*"It ensures a patient centred approach is maintained."* – Medical oncologist *"Our nurse keeps the multidisciplinary team involved and is proactive in new strategies to improve patient experience"* – Medical oncologist *"Care of whole patient - view from psychosocial view as well as from disease perspective"* – RN (ward)

	Confidant (3)	*"Patients may feel more comfortable approaching the nurse specialist, thus giving the treating team more info that they might not otherwise be aware of."* – Gynaecological oncologist *"Benefits are that patients tend to open up to nurses more than to doctors, therefore the CNS/CNC can advocate for the patient with having more knowledge of what the patient wants."* – Cancer service coordinator *"Many patients develop a bond with their specialist nurse which allows them to feel very comfortable when discussing complex and personal issues related to their cancer and treatment."* - Nurse practitioner
General benefits	General benefits (10)	*"Huge advantage when trained in details of unit model for treatment."* – Radiation oncologist *"Specialist knowledge, ensures best practice"* – Cancer service coordinator *"She is helpful on all levels."* – Medical oncologist *"Advanced disease knowledge and specialist skills"* – Cancer service coordinator
Disadvantages	Personal burden of role (1)	*"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

Other aspects of the special nurse role identified by treatment team members

Participants were asked if there were any other aspects of the specialist nurse role that they wished to comment on that hadn't been covered by the survey questions. Of the n=28 participants who responded to this question n=14 stated that there were no other aspects of the specialist nurse role that they wish to comment on. The remaining n=14 participants who responded to this question provided varied responses of which not all could be meaningfully categorised. Some responses were however categorised as depicted in Table 5.18 with all other responses coded to 'other aspects of role'.

Table 5.18 Other aspects of specialist nurse role identified by treatment team members

Category (n)	Participant examples
Need for specialist education for specialist nurses (3)	*"Access to education/secession planning - how to encourage less experienced peripheral team members eg ward staff. Smaller specialties eg gyn onc - how to find most appropriate education and courses."* – Cancer care coordinator *"Opportunities for nurses to further education in this specialist field - difficulty accessing specific specialist information."* – RN (ward) *"Need to have specialist qualification"* – Nurse practitioner
Definition and delineation of role (3)	*Would be [good] to get different groups to define what a specialist nurse is? Some believe they are relevant only in the outpatient setting for example.* – Gynaecological oncologist *"Ability to recognise own and role limitations. Ability to negotiate appropriate role expansion including initiating components of acute medical care."* – Radiation oncologist *"There tends to be a move towards generalised nursing intervention or care co-ordination in cancer that is diluting the specialised knowledge and experience on nurse specialists. The maintenance of specific CNC roles within gynaecological cancer teams is invaluable."* - Psychologist
Concerns for the workload of specialist nurses (2)	*"Sometimes the role is too much for one person to manage and there may be the need for more than one specialist nurse to share the role and provide appropriate levels of care and cooperation for all involved in the process."* – Nurse educator *"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) as the administrative model in large public hospitals no longer allows for expertise to be gained by administrative officers. Our institution does not allow for personal assistance for doctors so we can not trust that these tasks will be done properly. 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
Other aspects of role (7)	*"I find the specialist nurses very supportive and enjoy working with them. However we really need specialist nurses in other health aspects as well - don't have a breast, lung CNC."* - Researcher

	"Nursing research in survivorship" – Gynaecological oncologist *"I would just like to reiterate what a crucial role the specialist nurse plays for our team, for the ward staff and for the women and their families"* - Psychologist *"Knowledge of non-proven treatments and proven non-effective so called alternative "therapies"*- Radiation oncologist

No specialist nurse in team – explanations and perceived contribution

Of the survey participants identifying themselves as treatment team members, n= 19 stated that they did not have a specialist nurse working within their team. Of these participants, n= 18 commented on why they thought their service did not include a specialist nurse. The reasons participants identified for not having a specialist nurse in their team included that they already had experienced or specialist nurses working in their area, there was not the financial support available for such a role or there were not sufficient numbers of gynaecological cancer patients to justify the role. Examples of participant's comments are provided in Table 5.19.

Table 5.19 Reasons that team members did not have a specialist gynaecological oncology specialist nurse in their team.

Category (n)	Participant examples
Have other experienced or specialist nurses but not gynae-oncology specific (8)	*"Work at one hospital giving Chemo (and radiation is also given here) and the gynae Onc surgeon is at the other hospital 20 min away. I have no nurse support for these patients bar my Chemo nurses - I have 2 McGrath nurses for my breast cancer patients and the difference in level of support is so obvious. Despite us having clin Pyschol and social work at our centre - hence why I am doing this study to say Gynae Onc patients need more help ...."* – Medical oncologist *"We have a nurse practitioner and clinical nurse but not specifically for gynaecological cancer"* – RN (chemotherapy)

	"We have CNS's with interest in specialised cancer groups however are no employed for this group only and they look also after many other cancers" – Nurse Manager *"Our small regional team has a CCC, 2 breast care nurses and a clinical facilitator who assists all other patients"* – Nurse educator *"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"* – Community cancer support nurse *"In Radiotherapy we work with different tumour streams but we don't have to be CNS. We work closely with the gynaecologist Radiation oncologist but we also provide care to all the other patients coming in for treatment. This keeps us all skilled in other tumour streams as well, so that we can provide optimal care to all patients"* – RN (Radiotherapy)
Insufficient patient numbers to justify (3)	*"We have a smaller percentage of gynae cancer pt's compared to the rest such as bowel, prostate and breast"* – RN (Chemotherapy) *"The outpatient Day Unit I work in does not specialise in Gynae oncology. Having a specialist nurse would certainly enhance our patient care but I don't believe we would have the patient numbers to justify the position."* – RN (Chemotherapy)
Lack of financial support for role (2)	*"Certainly not because of a lack of want- most likely this relates to administrative willingness to financially support this role"* – Medical oncologist and cancer geneticist *"We have a CNS in Gynae Oncology who obviously just does Gynae Oncology, but in Medical Oncology our CNSs cover other cancers also. So our CNSs split their work around all cancers. Of course we would adore a gynae specific nurse specialist, but there is not the money available for this (and this would only be a part time position - not enough work for a full time gynae med onc CNS). I am well supported by our 2 outreach CNS- but these women only have the time to be involved with patients with complex needs (age/psychological/socail/co-morbididites etc) in patients on chemotherapy. The Gyn Onc CNS becomes involved in a few patients also"* – Medical oncologist
Other (4)	*"Sole practitioner"* – Gynaecological oncologist *"They are looking at employing a nurse for the role at present"* – RN (Chemotherapy) *"Historically there has not been a specialist Nurse as a part of the gynae oncolgy team at [name of hospital]. However there is a great need for one."* – Gynae-oncology clinical liaison nurse

Of the n=19 participants who did not have a specialist nurse in their team n=18 provided further comment on whether they thought a specialist nurse could make a contribution to their team. Three participants (n=3), 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. Given their role titles it may be that they themselves are playing the role of a specialist nurse within their team or providing a similar level of support to women with gynaecological cancers in their care. Table 5.20 provides the perceptions of treatment team members in relation to the possible contribution of a specialist nurse and the categories they were assigned to.

Table 5.20 Perceived contribution of a specialist nurse from treatment team members without one in their team.

Category (n)	Participant examples
Evidence of success of similar roles and in other tumour streams (5)	*"Yes, there is clear evidence that clinical nurse specialists provide additional specialised care for patients, but are also vital in assessing overall care pathways provided to patients in both the post-operative but also longer term following a cancer diagnosis."* – Medical oncologist and cancer geneticist. *"Yes - just look at how successful the McGrath model 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 *"YES. The Outreach Nurses and Gynae Onc CNS are an essential, integral part of patient care. They provide support, continuity, education and advice for the patient and help me enormously in following up and managing chemotherapy toxicity and complications. In the 3 years since they started I have absolutely no doubt there has been a huge improvement to the quality of patient care."* – Medical oncologist *"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

	"We have a McGrath Breast Care Nurse that visits 1 day a week and her contribution to our Breast Ca patients care is invaluable, I would imagine if we had a Specialist Gynae Ca. nurse the same would apply. The greater depth of knowlege and awareness of particular support services and one on one understanding has to benefit these ladies." – RN (chemotherapy)
Specialised care and support (5)	*"I believe they would be a valuable contribution. A specialist nurse would identify areas that can help those with gynaecological Cancer and support them and their families"* – RN (chemotherapy) *"Yes. A specialist nurse could provide the specific support needed to assist women with coping with thier diagnosis, treatment and journey as well as support psychosocial needs. While this is true for all cancers it is especially true for gynae cancers where body image sexuality and sense of self may be fractured."* – Nurse educator *"Yes, hopefully she would have more time to do the work linked to gynae patients care. In this Outpatients Radiotherapy treatment area the nurse linked to gynae does all the education and care for the gynae patients and also educated the other nurses on different procedures and care for those ladies"* – RN (radiotherapy) *"Yes - to provide patients with extra support"* – Gynaecological oncologist
Clinic support (2)	*"Yes, they could provide extra support in doctor's clinics and give valuable advice"* – RN (chemotherapy) *"Yes. Nurse led clinics would cut down patient wait time, and help the doctors manage their work load."* – Gynaeoncology clinical liaison nurse
Other (3)	*"Yes, our department is expanding and the patients from [name of hospital] will now start and finish their radiotherapy preparation and treatment in our department"* – RN (radiotherapy) *"Yes - being aware of current management to ensure the patient has support and information from a multidisciplinary approach - not just the doctors"* – Nurse Manager *"Yes, Cancer nurses and staff administrating chemotherapy must be competent. Unfortunately, not many nurses want to do a specialised course in chemotherapy or cancer Nursing."* – Nurse educator

Overall there was considerable support for the specialist nurse role from other members of gynaecological oncology treatment teams. A variety of perspectives on the specialist nurse role was gained with representation from all disciplines that are typically included in a gynaecological oncology treatment team

other than pathology. These results show that the role is highly valued by team members who perceive it to be of great benefit to the patients and their families particularly in regard to communication, coordination and continuity of care and support and advocacy. The role played by the specialist nurse within the treatment team itself was perceived by team members as one of leadership and cohesion, with the specialist nurse playing a key role in communication between disciplines. Treatment team members who did not have a specialist nurse in their team provided insight into the reasons for this with some citing that there were insufficient patient numbers to justify the inclusion of the role. However, some team members expressed concern that their patients with gynaecological cancers were disadvantaged by not having access to a specialist nurse as patients with other tumour types do. Though support for the inclusion of specialist nurses in the care of women with gynaecological cancers was identified through this survey, some participants warned that specialist nurses may 'take on too much' or compensate for deficiencies in the service overall, to the detriment of themselves and the patient who develops dependence on their care.

Chapter Summary

This chapter presented the results of an online survey completed by both specialist nurses and all other gynaecological oncology treatment team members. The data from the specialist nurses allows for an understanding of 'who' the specialist nurses working in gynaecological oncology in Australia and New Zealand are and 'what' they do to care for women with gynaecological cancer along the disease trajectory. Differences and similarities in the way that the role is practised between jurisdictions were identified and exposed the need to better define and standardise the role. The survey data enabled description of the practical elements of the specialist nurse role in gynaecological oncology and in turn will support better definition of the role. Data from the treatment team members provided a perspective never before gained

on the specialist nurse role in gynaecological oncology from this key stakeholder group. As demonstrated by the results, the specialist nurse not only cares for the women and their families but also plays an important role as communicator and collaborator within the treatment team. Overwhelmingly, treatment team members expressed that the care provided by specialist nurses was of benefit to the patients and their family. Specialist nurses play the role of 'central contact' for the patients and their families and offer continuity and support throughout their cancer journey. Participants without a gynaecological oncology specialist nurse in their team believed that this was a disadvantage to women with gynaecological cancers

Chapter 6 – Interview and focus group results

Introduction

This chapter presents the results of the analysis of data gathered from gynaecological oncology specialist nurses who participated in individual interviews or a focus group interview. The semi-structured interviews were aimed at determining the specialist nurses' experiences and perceptions of their role. A thematic analysis of the transcribed interviews was undertaken with four major themes identified from 23 minor themes. The majors themes 'Working between worlds'; 'The patient's go-to person'; 'When so much depends on one person'; and 'A clearer pathway' are presented in this chapter supported by participants' illustrations. Data relating to the characteristics of the interview and focus group participants and their current practices were also abstracted from the transcribed interviews. During the interviews and focus groups the participants were asked to introduce themselves and speak about their role and the service that they provide. While intended as an ice-breaker, the question yielded information about the participants and their current practices. These data were subjected to a content analysis and are presented in this chapter to provide background and context to the interviews and focus groups.

De-identification of participants

All participants were assigned pseudonyms and names of organisations and places were removed from transcripts to ensure the protection of participants' identities. Pseudonyms were assigned based on the type and number of the interview for example: Focus group 2, participant 3 (FG2-P03), Interview participant four (IP-04).

Interview and focus group participant characteristics and current practices

A total of 19 different specialist nurses participated in 13 individual interviews and two focus groups. All interview and focus group participants were female. Two of the specialist nurses participated in both a focus group and individual interview. Focus group one (FG1) included two specialist nurses and focus group two (FG2) included six participants. Four of the individual interviews were conducted in person in locations selected by the participants and nine were conducted via telephone. Purposive sampling was employed until all states and territories of Australia and regions of New Zealand where gynaecological oncology services are offered were represented. Interview and focus group participation rates are included in table 6.1 below. Table 6.2 shows the roles held by the interview and focus group participants.

Table 6.1 Participant numbers by state/country

State/Country	**No. of participants**
Victoria	6
New South Wales	3
New Zealand	3
Western Australia	2
Tasmania	2
Queensland	1
Australian Capital Territory	1
South Australia	1
Total	**19**

Table 6.2 Participant numbers by role

Role Title	No. of participants
Clinical nurse consultant	8
Nurse coordinator	4
Clinical nurse specialist	3 (all NZ)
Cancer nurse specialist	2
Liaison nurse	1
Gynaeoncology nurse	1
Total	**19**

Points of care

The points along the disease trajectory at which the specialist nurses entered and exited a patient's care differed among the interview and focus group participants and was largely dictated by the employing organisation. Some were involved from the very first contact that the patient had with the service and were responsible for triaging them into the service. Some specialist nurses did not become involved with the patient until a diagnosis had been made and they had been referred on from the multidisciplinary team. Where surgical services and oncology services were provided at different sites there was sometimes a specialist nurse to care for the patient during their surgical stay who would then hand over to the specialist nurse working in the oncology setting – thus the patient may have two specialist nurses during the course of their care. The specialist nurses who were the patients' designated coordinator of care tended to be involved across the full trajectory of care whereas the specialist nurses who worked

alongside a designated coordinator had more clearly defined entry and exit points. Despite this there was consensus from the interview and focus group participants that patients should have access to a specialist nurse throughout the entire trajectory of their care and most said that they were available to the patient at any stage. Table 6.3 shows the points on the disease trajectory when each interview and focus group participant is involved in the care of women with gynaecological cancers.

Table 6.3 – Points on continuum of care that each participant provided care to women with gynaecological cancers.

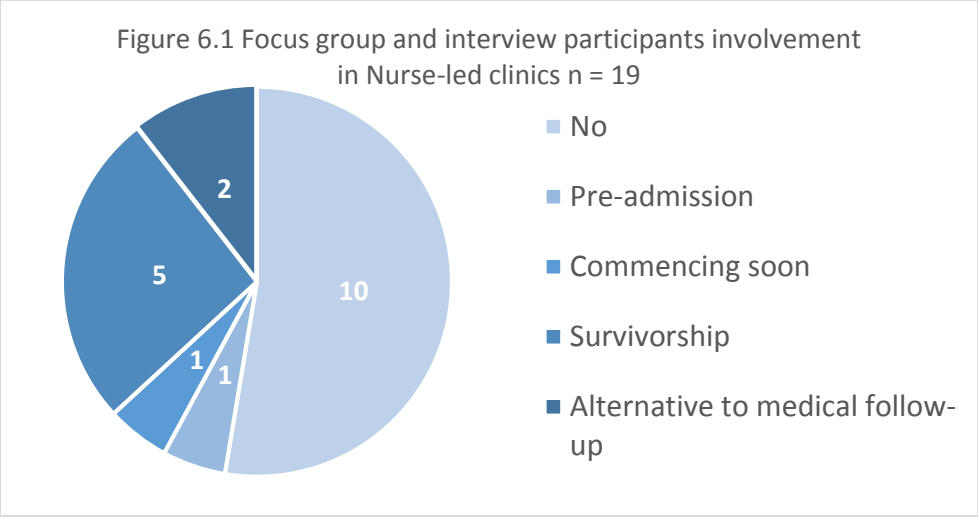
	Pre-diagnosis/ Pre-admission	Diagnosis	Surgery	Chemotherapy	Radiotherapy	Treatment of recurrence	Survivorship	Palliative care*
IP-01				-	-			-
IP-02	-	-	-					-
IP-03								
IP-04				-	-			-
IP-05								
IP-06	-		-	-	-			-
IP-07				NS	NS		NS	-
IP-08								
IP-09				-	-			
IP-10	-	-	-					
IP-11				NS	NS			NS
IP-12								
IP-13			-					
FG1-P01				-	-			-
FG1-P02				-	-			
FG2-P01	-							
FG2-P02				NS	NS			-
FG2-P03	NS							
FG2-P04	-			-	-	-	-	-
FG2-P05	-	-	-	-	-	-		-
FG2-P06								

Involved in patients' care at this stage - Not involved at this stage NS Not specified

*Denotes active involvement in the provision of palliative care. Many nurses explained that they were however involved in referring patients to palliative care services.

Nurse-led clinics

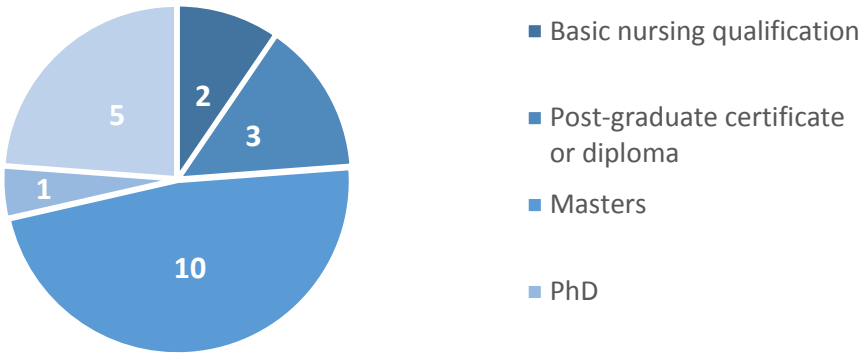
Eight of the specialist nurses involved in either a focus group or interview conducted nurse-led clinics and one nurse was in the process of setting up a nurse led clinic. Some participants stated that they would like to operate a nurse-led clinic but there were not the resources or support to do so. Of those who conducted their own clinics, one participant ran a nurse-led pre-admission clinic and five participants ran survivorship clinics in conjunction with follow-up from the patient's medical specialist or GP. The survivorship clinics were for endometrial cancer patients at low risk of recurrence (also low-risk cervical cancer patients in the case of one participant) and had an educational and needs assessment focus. In most cases the clinics did not involve physical examination of the patients or vaginal examinations. The other two participants ran nurse-led follow-up clinics that had taken over the follow-up of some patients at low risk of recurrence from the doctors. One of the participants saw low-risk endometrial, cervical and ovarian cancer patients and the other saw only low-risk endometrial cancer patients. In their clinics they performed physical examinations, vault smears, ordered tests and reviewed and communicated test results. These clinics ran at times when a consultant was available so that they could be called upon for a second opinion or to write prescriptions as needed. Figure 6.1 depicts the interview and focus group participants' involvement in nurse-led clinics.



Education

Interview and focus-group participants were not explicitly asked what their highest qualification was during their interview, but this was revealed by most participants while discussing the education needs of future gynaecological oncology specialist nurses. The specialist nurses had self-directed their education to meet the needs of their role. Their current education practices ranged from working towards a Master's or PhD, regular attendance at conferences, family planning courses and acute care courses. One nurse reported travelling to the United Kingdom to attend a gynaecological oncology-specific nursing course. Figure 6.2 shows the highest qualification held or currently working towards by the interview and focus group participants. Five (n=5) participants did not specify their highest qualification during the interviews.

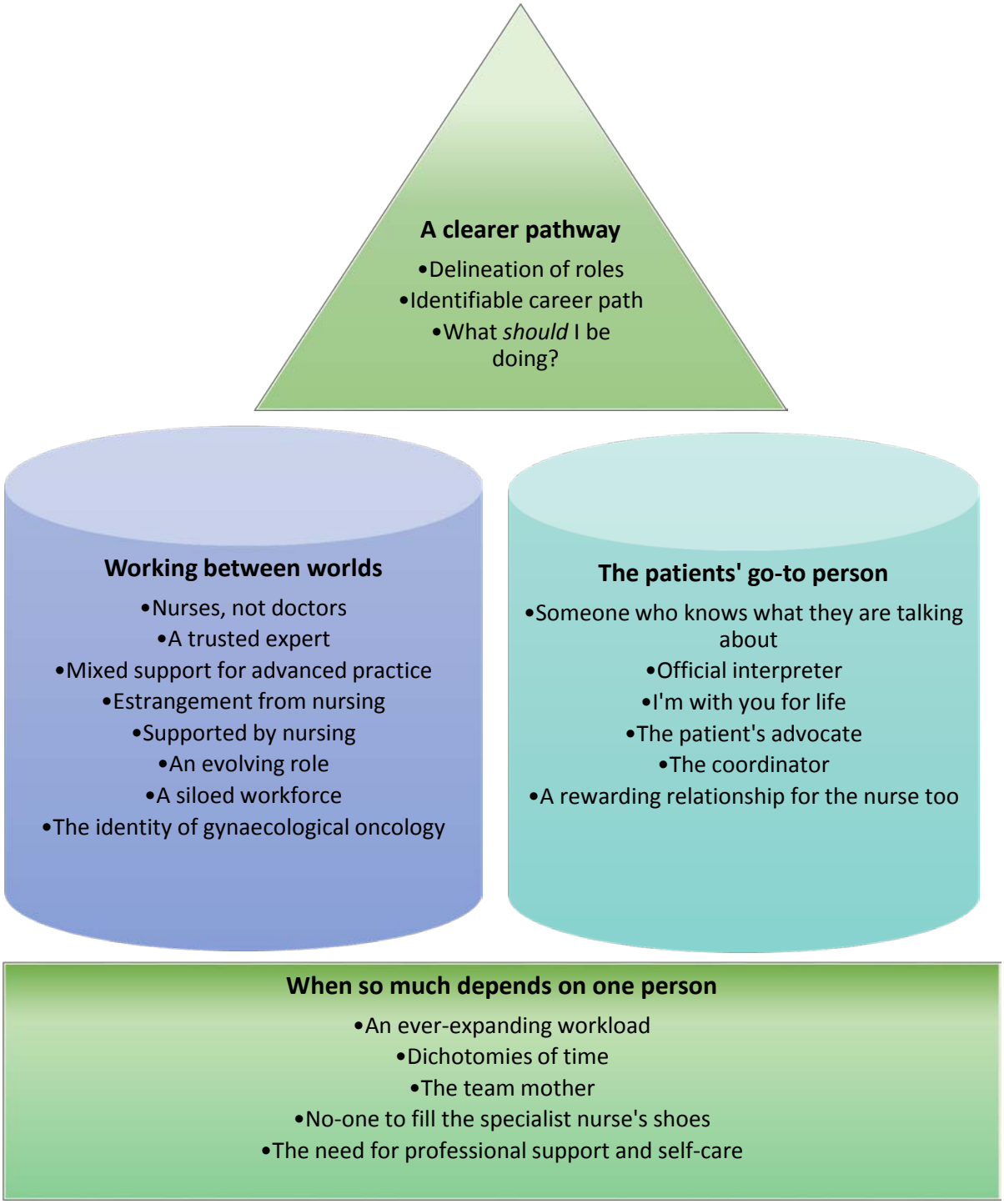
Figure 6.2 Focus group and interview participants' highest qualification
(held or working towards) (n=19)



Gynaecological Oncology specialist nurses' experiences and perceptions of their role

Data identified as relating to the specialist nurses' experiences and perceptions of their role were thematically analysed. Four major themes were inductively derived from 23 minor themes. Figure 6.3 provides as visual depiction of the themes that are described in detail below.

Figure 6.3 – Map of major and minor themes relating to specialist nurses' experiences and perceptions of their role



‘Working between worlds’

The theme ‘Working between worlds’ relates to the metaphorical space that gynaecological oncology specialist nursing work occupies. Through advanced nursing practices, such as nurse-led clinics, specialist nurses are working somewhere in-between the scope of practice of nursing and medicine. Some gynaecological oncology specialist nurses saw themselves as a ‘nurse in a medical team’ whereby they officially reported to a nurse manager but operationally sat within a medical team. Despite reporting that they felt respected by their medical counterparts who trusted their expertise, some participants also experienced subordination. The participants who work within a medical team experienced challenges in meeting their remit as nurses as their role continued to evolve and extend to include duties previously completed by medical staff. For some, this led to a lack of support or estrangement from their nursing managers. The participants perceived that they either did not understand their role or did not support their advanced level of practice. Other specialist nurses were well supported by their nurse managers and did not experience the challenges of working between the ‘worlds’ of nursing and medicine to the same extent. Although some formal avenues of communication exist for gynaecological oncology specialist nurses, many felt that they worked as ‘silos’ and had little awareness of the activities of specialist nurses outside of their organisations. Several participants experienced challenges relating to the fact that the field of gynaecological oncology, in medicine, is a sub-speciality of obstetrics and gynaecology. Gynaecological cancer patients are often treated on Maternity and Gynaecology wards, yet specialist nurses need to work within and between the ‘worlds’ of both gynaecology and oncology which posed challenges for some of them. The eight minor themes from which ‘Working between worlds’ was derived are discussed in more detail below along with participants’ illustrations.

'Nurses, not doctors'

The minor theme 'Nurses, not doctors' relates to the challenges of gynaecological oncology specialist nurses in maintaining their remit as a nurse whilst working within a medical team. While most interview and focus group participants officially reported to a nurse manager (at various levels), several of them reported that, functionally, they were supervised by a gynaecological oncologist. Participants expressed that the doctors they worked with did not understand their responsibilities and obligations as nurses or what it is to be a nurse.

The challenges that I face I think are that I'm a nurse in a medical team…And the doctors don't know necessarily what nurses do…And so they kind of have a rough idea but they haven't grown up in that world so it's a bit different… So although we work in a medical team we're still managed separately and that can be challenging… I kind of see nursing and doctoring getting closer and closer together the older we all get but there is a separation still –IP-02

He's got no concept of nursing [Supervising gynaecological oncologist]. He doesn't understand, he has no idea of the intricacies of nursing... Sometimes I try and sort of talk about projects I'm doing and he looks at me blankly and says, "Why would you be doing that?" You know "Who cares?" Risk assessments involved in those sorts of projects around falls risk and pressure injury risk obviously have to be involved. Medicine don't even know that's done, that sort of stuff. – IP-04

One specialist nurse explained how her nurse-led clinics, which follow-up low grade endometrial and cervical cancer patients, were born out of a need to relieve pressure on the medical team and allow them to focus on new patients and those with more advanced cancers.

And I think understanding of the medical profession that if you are going to be doing the roles, as in those additional roles… that are actually sort of relieving them of some burden, that you're actually not going to do it like they would. There's got to be some scope that you do it as a nurse and not as a pseudo-doctor. – IP-04

One nurse recognised however that a nurse cannot complete a clinic the same way that a doctor would. She also highlighted that as a nurse, patients were more likely to share sensitive information with her during the consultation which in turn must be managed from a nurse's perspective.

So they [the patients] don't tell the doctors what they tell us, because we're a nurse, because they think we've got more time. And they'll say things like, "oh I feel I can tell you"… I was really [thinking], this is wonderful…I feel so valued… but now I've realised what a burden it is. And it's like, please don't tell me anything else because I'm going to have to follow it up. And the referrals that you have to make and the follow-up phone calls. I'm now being criticised again by Medicine for, I've got to pull back from that, I've got to just hand that over to GPs. So it's really interesting how when Medicine will allow us to do what we do, but within what they would consider their domain of practice, how we've actually got to do it how they do it. - IP-04

Some specialist nurses have thus found themselves in a position where the boundaries of nursing and medicine have become blurred and their practice has advanced with or without the support of nursing and/or medicine.

'A trusted expert'

The specialist nurses discussed how their knowledge and expertise were acknowledged by the gynaecological oncologists they worked with. Several of them assumed some responsibility in 'training' the junior doctors in the service and saw themselves as having more knowledge and experience.

The regard that the gynaecological oncologists had for the knowledge and expertise of the specialist nurses was evident in the following accounts:

We had an international [medical] *fellow two years ago…it was her first year in gynae-onc and she was from another country and the first six months were horrific. I was doing things that I'd never done before but it was because she had no idea what she was doing… the patients wouldn't have gotten what they needed if I hadn't of, and* [name of gynaecological oncologist] *acknowledged that and she had a pretty horrific six months too, like it was both of us stepping in and having to fill that* [gap]. - FG2-P02

You know, I guide the house surgeons and the registrars, they come to me when they can't find the consultant. And, one of the consultants who went on holiday said, "Well I wouldn't have gone if you weren't there." – IP-03

… quite often… you're teaching the doctors how to do these - when they haven't even done colposcopy courses themselves… my boss [gynaecological onocologist]… expects me to have taught the registrars or whoever what to do. – IP-11

You think, I know this is what needs to be done, and then I'll go to our Fellow or our surgeon and I'll say "I've told them [training doctors] that this is what's happening but they haven't done it. Can you go and tell them?"… it's like banging your head against a wall. – IP-09

Despite the specialist nurses perceiving that they had more experience and knowledge in the field than the doctors training in gynaecological oncology, one nurse recounted a conversation with the head of her department regarding remuneration where the 'value' of the specialist nurse did not translate in monetary terms.

…we had a bit of a problem with our two fellows…they [the department] ended up paying them well over $200,000 each because of overtime…and one of them was only… three days a week. So they've now agreed that they'll pay them as a junior consultant, because they can't claim overtime. So I commented then to my boss and said, "So that's about $180,000. Oh my God, well I wonder if I could get my remuneration packaged larger", and he said, "Oh, I think $100,000 for a nurse is excellent money". –IP-04

The same nurse felt that nursing is still seen as a 'bob-a-job'*[1], playing the role of general assistant to everyone within a multidisciplinary team meeting.

It's like these jobs just fall to me and if something goes wrong, I have to ring the company, "Why isn't it working? You need to get onto that tomorrow". And my answer to that wants to be, "I don't know why it's not working. You ring the company tomorrow. I don't care". But I go, "Okay, yep, sure". I think when you work with Medicine, they will never then allocate a job like that to doctors...And I think that's the big drawback for nurses working at high levels, is we're still seen as bob-a-jobs, general dogsbodies. –IP-04

[1] A 'bob-a-job' is a fundraising activity that involved boy scouts knocking on doors and offering to do jobs for one shilling

Thus, while the lines are sometimes blurred between nursing and medicine for the specialist nurses in relation to knowledge and expertise, there is a distinction between worlds when it comes to remuneration and administrative tasks.

'Mixed support for advanced practice'

Participants experienced different levels of support from nursing and medicine to advance their practice, particularly related to the institution of nurse-led clinics. Participants relayed the concerns of other team members as to whether nurse-led clinics were nursing roles or quasi-doctor roles. Specialist nurses reported that they were able to gain the confidence of medical staff to fulfill the role through the direct supervision of medical staff initially, and then running their clinics simultaneously with the doctors' clinics to ensure that medical advice was always readily available.

…there was certainly a bit of… difficulty getting that across the line from one surgeon perspective, one was sort of very much pushing for it and the other was saying, "Well, you know what qualifications or what skill level do you have? Are you just being a quasi-doctor to fill a gap and you know let us do something else? Or is this truly a nursing role that you can take on? And can we trust that the outcomes that you're going to have from seeing the patients are going to be the same as ours, and are you going to miss anything?" - FG1-P02

They would come in when I did an examination to ensure that what I was doing was what they expected to be done… and that they had the confidence that if I was having a problem or I had an issue or a concern, that I could come out and ask them. So the way my clinic runs is that there is always a doctor running a clinic simultaneously, so I can go out and say, "What do you think about this? Is this the right thing?"… So I'm not sort of running my own show in that respect, but have the time to go through a lot of

the other stuff with the patients about survivorship and lifestyle changes that can happen, that often the doctors can wash over...- FG1-P02

In relation to the institution of a nurse-led clinic, another participant reported that although their head of unit was supportive, some other doctors were more hesitant to support the new clinic.

…we had good support from - [name of gynaecological oncologist] was great. She wanted to actually be able to put private patients into the clinic as well because she thought it was worthwhile. Our other two consultants, while they took it up, they took a little bit longer, they're a little bit more conservative… I think they… just wanted to be assured that nothing would go wrong... – FG2-P02

Another participant discussed how their nurse-led clinic was not just taking over some of the doctors' follow-up work but was also providing supportive care to patients through screening and making referrals while also making a cost saving for the organisation. The importance of having support for the project from the head of department was also mentioned.

…our clinics, they're huge here as they are and so having some of these patients come out of that standard care that didn't really do a whole lot to offer referrals apart from the check-in and off you go. So I suppose it helps to ease the burden a little bit in that way but [name of gynaecological oncologist]…was a huge driver of that project happening and I think you really need you know buy-in and support from your heads of unit to make those sorts of things happen. You know, if you can show a cost saving in an organisation, it's so much the better…. –FG2-P05

On the contrary, one participant had the support of her medical supervisor but not of her nursing managers as her scope of practice advanced.

… that [progression of the role] *actually caused quite a lot of animosity within nursing because I was seen as being working at a level that I shouldn't have been working at…once I did my masters, I applied for a nurse specialist role, which I got.. but I was still criticised by nursing management, for working above* [what was thought to be] *my capacity. So it was very difficult…*IP-04

The lack of support from nursing management felt by this participant led to an alienation from the discipline of nursing within their organisation, also felt by other participants, that is explored further in the following minor theme 'Estrangement from nursing'.

'Estrangement from nursing'

This theme relates to the alienation or estrangement from the nursing team that some participants felt in their largely autonomous role as a specialist nurse. The specialist nurses felt that nursing management within their organisation and sometimes nurses working on the floor did not value their role or understand what it is that a gynaecological oncology specialist nurse does. Some participants felt that nursing management was not on their "wavel*ength"* or came from a different specialty of nursing and thus had little understanding of gynaecological oncology. One specialist nurse suggested that the lack of support from nursing management was due to the lack of clear pathways for nurses with specialist roles just added to the nursing career structure along the way.

I love working with the medical practitioners that I've worked with. I think they're brilliant and they really value my role. What I dislike is that from a nursing perspective, I don't know that it's not valued, I think it's not understood and therefore not applauded and not recognised for the complexity that it is. IP-05

…it's not rejection, but it's a bit of alienation from nursing colleagues who aren't working in these roles…I don't know whether that's because they just don't know what we do, and we really struggle to articulate it because we do so much. Or whether it's because they feel like they're doing their job and they don't need us. But I mean I don't know what that is. –IP-05

…a couple of managers ago... we really… clashed because she actually saw me as a threat which I wasn't trying to be. She really found…my knowledge to be quite threatening to her and that made the relationship quite difficult… - IP-09

Two specialist nurses shared similar strategies for overcoming the lack of understanding of their role among their nursing colleagues. Both were regularly involved in presenting gynaecological cancer patient cases or aspects of their role to groups of nursing colleagues from other nursing specialties such as midwifery.

…so you need to get up and you need to tell a story. First of all I said, "Indulge me, I don't think any of you know what I do. I'll tell you... "I didn't do a slide about my story but I'll tell you the whole story," and they all came up and said, "Oh, congratulations, it was great, great story. We want to know the outcome." FG1-P01

It's about getting yourself and your role out there. We have like a… daily divisional in-service and I put myself on that calendar a couple of times a month, and the midwives have to sit there

and listen to gynae oncology stuff…you get some amazing questions from them and yeah they come away thinking that's fantastic because I didn't know that that's what you did and I didn't know what women go through. FG1-P02

One participant who felt animosity and a lack of support from her nursing managers in regard to her role counteracted this by becoming a mentor to younger nurses.

So although I don't feel I get any professional support from nursing, I am very conscious that I need to do that, and I really want to provide that for some of the more junior nurses. IP-04

This experience contrasts the experience of other nurses who felt that they had the support of nursing as described below under the theme 'Supported by Nursing'.

'Supported by nursing'

Whilst several participants had the support and backing of their medical colleagues, others felt strongly aligned with and supported by their nursing managers. The specialist nurses in roles that nursing management took ownership of, and were actively involved in, felt supported and a part of the nursing team.

*I don't have that connection so much with the medical stuff. I obviously work with them and I liaise with them and we talk on a daily basis, and yeah there's a close relationship there. But I don't have that… I don't have that real obligation to the medical staff. My obligation is to my nursing managers...*IP-10

A lack of support from nursing management added stress to the role. One participant who had been in the role for over 21 years described how it was important to have the support of her nursing managers as she had not always experienced the level of support she had.

I think it's obviously progressed over the time… I was just saying to someone at morning tea that it's changed… with the nursing unit manager, we have on our ward. Over the years we've probably had four and…I've never felt as supported and as part of the ward management team than I have now… She's really interested and…seeing me as…the clinical expert for gynae and gynae oncology - IP-09

Yet the support of nursing to fulfil the role was limited for some nurses. One participant explained that her role was funded from the surgical ward budget and while this meant she felt a part of the nursing team, she was often required to fill in sick leave on the ward and did not get relieved when on leave herself.

…we don't get back fill for any of our annual leave, long service leave, any of that. …if there's need for… ward staff, you know for sick leave and things we get pulled out there. …when you provide a service, you need to provide that as an ongoing service and it is extremely frustrating… at the end of the day…they've got a budget to maintain. - IP-12

Another specialist nurse would often be asked to complete general clinical tasks on the ward when ward staff were busy.

Do you find that you all get extra bits put on your - Like, "Can you do the blood transfusion?" - FG2-P01

Thus, support and involvement of nursing managers in the specialist nurse role seemed to have some limited influence on whether participants felt supported overall in their role.

'An evolving role'

As the role of a specialist nurse in gynaecological oncology is a relatively new one, many of the participants have held the role since its inception and report to have 'made it up as they go along' given the lack of guidelines to support such a role. This theme considers how some specialist nurses have evolved their role from performing like a doctor's assistant to a true nursing role and the challenges faced when creating a nursing role from scratch.

Some specialist nurses reported the origins of their role as being one of a 'doctor's assistant' whereby the gynaecological oncologist needed the support of a nurse and sought out a nurse to complete the role. The roles have since evolved into clinical nurse consultant roles.

I started working with… the director of the department… as a clinic nurse, and from that evolved [to] me becoming like his clinical assistant, nursing clinical assistant. Just the role progressed to where I was given more responsibility because I proved myself to be very interested and I'm actually good at what I do. - IP-04

It was the surgeon at the time who said, "I need a nurse," and at that stage, she was called the "resource nurse," and did a bit of everything, and then she sort of moved on to different pastures, then I came into that role. At the beginning, it was a clinical nurse specialist role and then over time, it's changed to a clinical nurse consultant role. – FG1-P02

… when I started and took over the other girl's role 20 years ago I just used to follow our surgeon around like a little puppy. He said "Jump." and I said "How high?" and it's very much changed from that. Yes, I certainly still go on ward rounds now but I have a different role within that ward round than I did before. I was carrying the charts and handing things to the doctor and all this sort of stuff… don't do that anymore. I'm there to see the patient from a nursing perspective on that ward round as opposed to just doing what the doctor says. - IP-09

With no clear guidelines in place, specialist nurses have had to invent their roles as they went along and in many cases adapt their role to the changing needs of their employing organisation. Some nurses highlighted the challenge of coming into an ill-defined role from more traditional nursing roles that have clearer boundaries.

…you've got a new job … so it was like nobody could tell me what to do. And, I wanted to know that… there was evidence for what I was doing and I was doing the right things for the role. - IP-03

…initially, and probably still… there was no structure and no kind of firm way that the job was going to be done, so I found that I was always reinventing myself to try to figure out, you know, how to best do the role… there was not much… description about what the role was going to be. - IP-13

Another specialist nurse discussed the need to re-focus the role to ensure that it is a nursing role.

When they established the roles… they didn't really know what the role would be. And I think the difficulty that I faced more than anything… is changing the role…moving the role away from

administrative tasks to nursing related activities… and the expectations of what that role will be…because… a few years ago, the nurses were taking on a lot of non-nursing duties… whilst now, we're trying to shift it to be more a nursing role. – IP-08

Over time, the specialist nurse has thus had to develop and mould their role to be a 'nursing' role and not an administrative or doctor's assistant role. The role itself, being autonomous in nature and bespoke to the employing organisation, is isolating for some specialist nurses as explored in the following theme 'A siloed workforce'

'A siloed workforce'

It was evident through the interactions of the specialist nurses in the focus groups and between the interviewer and some participants, that the workforce of gynaecological oncology specialist nurses throughout Australia and New Zealand work as 'silos', having little contact with each other. While some formal avenues for communication and interaction exist between the specialist nurses, such as the organisations through which some were recruited for this study, some participants were not active members or even aware of these. For some specialist nurses, certain interview questions seemed to be informative, highlighting how some participants worked within the confines and needs of their employing organisation. It was clear that the interviews were also 'cathartic' for some who otherwise had never had the opportunity to discuss their role in that way. The focus groups were utilised by some participants as a forum to compare and validate their experiences in the role with their peers. A few focus group participants worked together or had occasional contact with each other to seek advice on patients. However, many participants expressed a desire to have more contact with other gynaecological cancer

nurses in the future.

… because I do work in silo… we've got breast nurses who work in silo, lung cancer CNSs who work in silo, I work in silo. We're not part of a, you know, oncology network of CNSs. – IP-03

… ideally, it would be great to be able to set up some sort of network of our own… people doing the same roles without having to reinvent the wheel… work towards a body to be able to… Look at patient information that we give out to patients. Look at things like length of stays. Comparing… all that sort of stuff with each other… What you give and when it's appropriate to give some of the resources that we provide to patients and their families… so all these things, it'd be great to be able to bounce off people – IP-12.

One specialist nurse, who had only been in the role for six weeks, was not aware that there were no practice guidelines or models of care in place for gynaecological oncology specialist nursing care and found the interview to be informative.

There currently isn't any, is that what you're saying? … So there's no actual standardised guidelines across Australia?... Thank you so much for your questions because they're thought-provoking and hopefully things will come out of this study that will actually help this role. – IP-07

Likewise, another specialist nurse who had completed a Master's degree for nurse practitioners was not aware that other specialist nurses in gynaecological oncology had also done so.

… so there's someone else that's done their nurse practitioner that's doing this job?... I thought I was the only one. – IP-11.

For one nurse who had little support in her workplace or opportunities to debrief, the interview was beneficial.

And I probably think that that's why with this, I sort of blabbed into it because it was almost like a catharsis, I could say it. It's completely confidential, so beg my pardon if I blurted into it too much, but it is. – IP-04

Focus group participants were keen to learn about each other's experiences as a means of validating their own as demonstrated by this interaction regarding unpaid overtime:

FG2-P03*:* *Am I allowed to ask questions?*

Facilitator*:* *Yes absolutely. It's meant to be interactive.*

FG2-P03: *I'm interested that you say ten hours, because you're only paid for eight.*

FG2-P02: *Yes.*

FG2-P03: *So, what happens with those two hours?*

FG2-P02: *They're my hours that I give.*

FG2-P01: *So, we're all the same.*

Co-facilitator: *Do you ever get to take a day off in 'time in lieu'?*

FG2-P02: *Every now and then.*

FG2-P05: *When you're not getting hassled to take out ADOs?*

Participants all expressed how eager they were to learn more about other specialist nurses' roles.

'The identity of gynaecological oncology'

Just as the specialist nurse in gynaecological oncology worked between the worlds of nursing and medicine, so too the role existed between the medical specialties of obstetrics and gynaecology and oncology. As gynaecological oncologists initially train as obstetricians and gynaecologists before moving into the sub-speciality of gynaecological oncology, many still operate on women with non-malignant conditions and hospital wards are structured around this. Participants reported feeling frustrated about how gynaecological oncology often sits within maternity and women's health departments, separate from other oncology services. There was a perceived dominance of maternity in these settings which was frustrating for the specialist nurses responsible for ensuring that the complex needs of gynaecological cancer patients were identified and met.

…we've got one foot here in obstetrics and gynae - whereas when you work in oncology… everybody's thinking along the same lines. They're oncology…that's their focus… but… with people from obstetrics and gynae… they don't always think on your wavelength. - IP-11

The struggle for recognition of gynaecological oncology within a hospital was also evident in the recount of two focus-group participants in relation to a re-structure of their hospital. The 10 beds usually allocated to gynaecological oncology patients within their women's ward were not included in the hospital re-development.

… they had just rubbed out the women - the ten beds…and they were just going to be sprinkled in with men and all sorts of stuff - FG2-P03

Just as gynaecological oncologists have a unique identity shared between gynaecology and oncology, gynaecological oncology specialist nurses held a similar dual identity requiring them to

cross over the traditional nursing career pathways of surgical nursing and oncology nursing. Unlike medicine however, where gynaecological oncology is a formally recognised speciality, there is no formal way of identifying as a gynaecological oncology nurse. There was some difference in whether the specialist nurses identified themselves as gynaecological oncology nurses or surgical or oncology nurses.

….you know I've had conversations with my surgical colleagues from other countries that actually I'm probably not a gynae-oncology nurse specialist anyway, they don't like to think that a nurse that's never worked as a surgical nurse can call themselves a gynae-oncology nurse specialist. - IP-02

So I identify as a surgical oncology nurse… it's really interesting, most surgical oncology nurses don't identify as oncology nurses either. – IP-04

Whilst the wards that gynaecological cancer patients are treated on are structured around the medical speciality of Obstetrics and Gynaecology, the nursing care of these women interfaces with oncology and there was not always an obvious career pathway or role identity available to specialist nurses working in this field.

The major theme 'Working between worlds' considered where, in a metaphorical sense, the role of the specialist nurse is placed in gynaecological cancer care. The advanced nature of some specialist nurses' work, and the fact that they are often a nurse working in a medical team, left some specialist nurses feeling distanced and unsupported by the discipline of nursing within their organisations. It was challenging for some participants to fulfil their remit as nurses when working within a medical team. The autonomous nature of their work further added to their isolation and it was evident that many were

working as ‘silos’ throughout Australia and New Zealand, unconnected to each other. Despite reporting that their experience and expertise was recognised by the gynaecological oncologists that they worked with, some still experienced subordination when it came to administrative tasks and remuneration. Forging an identity as a gynaecological oncology specialist nurse was difficult for some participants when gynaecological oncology services were located within maternity and gynaecology wards. Traditional surgical and oncology nursing pathways made identification as a gynaecological oncology nurse contentious.

‘The patient’s ‘go-to’ person’

Specialist nurses were clear on the role that they played in providing supportive care to their patients. The specialist nurse saw themselves as the patient’s ‘go-to’ person, accessible to the patient whenever they needed help throughout their cancer journey. The specialist nurses discussed their role as patient advocate within the treatment team and how they would interpret and reiterate medical information for patients. Just as their medical colleagues saw them as an expert, the specialist nurses also believed that they offered easily accessed knowledge and expertise to the patient. Some participants discussed how they formed long-term relationships with some patients, which was rewarding for the specialist nurses and the patients alike. Many specialist nurses specified that being the point of contact for the patient was highly emphasised and fulfilling. Others acknowledged that not all patients required or desired the services that they offered and that patients should be encouraged to self-manage their care, discouraging dependence on the specialist nurse.

'Someone who knows what they're talking about'

Participants highlighted the need for them to have advanced assessment skills and overall knowledge of gynaecological cancers in order to be 'someone who knows what they're talking about' with the patients. They believe that having the skills and knowledge to 'answer off the top of their head' (IP-02) was valuable and reassuring to the patient. The experience of the specialist nurses allowed them to respond to patients' queries confidently and decisively as they have a thorough understanding of the patient's situation and likely outcomes. When the specialist nurse didn't have the answer to a patient's query, they felt that it was important that they had the skills and know-how to find out. Easier access to the specialist nurse in comparison to the doctors was also perceived by the specialist nurses as an important offering to the patients.

…you have to have advanced knowledge and skills. So, I do a lot of triaging over the phone… you've got to really be able to… pick from them what their symptoms are, work out what's going on, organise a CT, organise bloods, explain to them what you think is going on and get them back into the system – IP-03

…to have that relationship and to have their trust, you do need to be a clinical expert… I don't know all the latest research… but I have a fair idea of much of it. So, if somebody rings with me with a question that they've heard about, if I don't know about it, I'll say to them, look let me do a little bit of searching and I'll come back to you. – IP-03

So I think it's about that ability [the patient's] to be able to ask questions and to know that [the patient's questions] will be answered from a viewpoint of someone who knows what they're talking about…knows the pathway that they'll have to take…that coordination of care… they've got someone to call. - IP-04

The specialist nurses sometimes found themselves in the position where the information that the patient had been given in the community prior to admission for treatment of their cancer was incorrect and there was a need to quickly establish the trust of the patient and provide the correct information.

…a lady rang the other day… she'd been told by her GP that she had stage four cancer and she was going to die. And I said "I need to go back around to our doctor's office and find where your information is." and she said "So are you the right person to talk to or are you not"…Then I rang her back. We talked for 20 minutes and she said "Oh, you were the right person. Thank you so much"… She's got an early stage endometrial cancer. - IP-09

…your GP might have said, 'Yes, you need a hysterectomy,' but this is actually the plan…we need to do an EUA and MRI, and a PET scan before we actually make any treatment decisions to see where your disease is at." So it's about almost… re-educating… them, taking back what the GP or the referring doctor has said… I think [being involved in the patient's care] *from the very beginning is important.* - FG1-P02

Just as the specialist nurse utilises their knowledge and experience to answer their patient's queries, they play the role of 'interpreter' throughout their relationship with the patient, ensuring that the patient understands their prognosis and treatment as explored in the following theme 'Official interpreter'.

'Official interpreter'

Several of the specialist nurses explained how they routinely 'interpret' or reiterate what the patients have been told by their doctors, particularly at the point of diagnosis. The specialist nurses reported that

the patients and their families were not often able to absorb the information initially provided to them and often sought further information and clarification from the specialist nurse. Likewise, the patients may consent to their treatment but seek further information or 'interpretation' from the specialist nurse.

I might ring a doctor and say, "This lady is very confused," and they'll say, "But we told them," but they would have spoken in, not in people talk; they speak in doctor talk. And a lot of patients don't understand it. And I think a lot of people, once they hear the word "cancer" they don't hear anything else. - FG1-P01

… so it's a lot of just going back over information and things like that and you need someone who knows… the woman and the family, and enough information about the cancer to be able to link everything together, so I think having someone there is really important, that can't just be anyone. – FG2-P02

So, they may well see a surgeon or a medical oncologist, and they may well have information passed, but quite often the woman will ring me and say, "Can you explain it again to me? Can you explain to me exactly what they mean? And, what does the clear cell mean? Why have they told me I've got a clear cell cancer? I thought I had cancer of the uterus, so it's being able to explain to patients in a language that they understand, exactly what's going on, and be able to explain to them the pathways. – IP-03

One nurse spoke of filling in the gaps after the patient's consultation with the doctor, ensuring that they received holistic care with the use of a formal assessment tool to identify and meet the patients' needs.

I do believe that doctors are under far too much pressure to achieve what they have to

do at consultation and somebody has to fill in all the other gaps. I think nurses are very well placed to do that, the oncology specialist nurse. Every unit needs to have a specialist nurse to provide the patients a holistic needs assessment, a point of contact. – IP-06

Following up with patients after they've signed a consent form for their treatment was a practice of one of the nurses.

…we run the gauntlet of informed consent in our department because I listen to a lot of it being said and I watch a lot of consents being signed. And then I do a follow-up interview with the patients about information about coming into hospital, about their surgery, about their recovery, but within that is about, "You've signed this consent. Do you understand what you've signed?" - IP-04

Just as the specialist nurse acts as 'interpreter' for the patient, they're also the patient's point of contact with the gynaecological oncology service, throughout their disease trajectory and into survivorship. This is explored further in the theme 'I'm with you for life'.

'I'm with you for life'

The specialist nurses described how they provided patients with a point of contact – someone in the system to call with questions and concerns, at any point along their disease trajectory. Some of the participants believed that being a point of contact for the patient was the most important aspect of their role. As treatment for gynaecological cancers can be multi-modal, the specialist nurses reported how they needed to coordinate the patient's care and be available to assist the patient to navigate their way through the system. They made themselves accessible, offering multiple ways a patient could contact

them. 'I'm with you for life' relates overall to the reassurance that specialist nurses believed they offered patients.

…it's the card with the phone number on that is the most important thing we offer people – IP-02

I then follow the patients through, so I am their link. They have my phone number, they know multiple ways of contacting me, email, page, my work mobile and my office, and I follow them right through. So they know that they can contact me six months later. – IP-04

…everybody gets my phone number. Those that choose to ring, ring, and those that don't, as well as, and I will always say, "Give my number to your family if they have any questions. You do this once; I do this every day. Ring me. No question's a stupid question because you're new to this whole game," so that's what we're here for, that's what our role is about…supporting the woman and their family. - FG1-P02

In comparison to contacting the specialist or the GP, specialist nurses felt that they offered patients a point of contact who knew them and their story and could provide trusted advice.

…you can almost see the relief across their face when they know they can actually ring someone that isn't just the doctor…Definitely just being a point of contact, I think, is one of the most important [aspects of role]*. I think sometimes just a phone conversation with these ladies just helps so much that, you know, crises can be averted entirely…. there's no one designated to that role if we didn't exist - there would be no-one to talk to. And the doctors - I mean, you could get them but it would be hit and miss, I think.* – IP-07

The specialist nurses who participated in focus group two discussed the importance of establishing a rapport with the patient from their first point of contact with them and through their inpatient stay that ensured the patient developed a trust in them as their 'go-to person', as summarised by one participant below:

And then they have that trust and they know then exactly who to contact and who to ask questions and you can find things out for them to make sure that they don't fall through the gaps. FG2-06

The specialist nurses described how they made themselves readily available to the patients, no matter where they were on their disease trajectory and would be contacted by patients many years after their treatment. Specialist nurses believed that the fact their service was available to patients beyond treatment and that they could be contacted any time the patient needed was reassuring to patients. Whilst the specialist nurse may not formally follow-up with the patient beyond their standard schedule with the medical specialists, they were available to the patients if needed and made this known to them. One specialist nurse also spoke of patients checking in with her over the years despite not having a clinical reason to do so.

…when I meet people I say, I'm with you for life -you can call me at any time. And I haven't run into problems I have to say… I haven't had a huge backlog of patients causing me issues. They know that they can give me a ring if they've got concerns way down the track. IP-10

One lady travels around Australia in her Winnebago and has been doing that for 10 years; she was also a stage four ovarian cancer, and she rings me to say you know, my CA 125 is perfectly normal. - IP-01

Some nurses, however, did acknowledge that not all patients needed their services and one participant believed that the specialist nurse should assist the patient to move their focus from illness to wellness in the survivorship period and facilitate self-management from the beginning of their care. Although the participants stated that all patients are given the contact details of the specialist nurse, not all women utilise their services or remain in close contact with the specialist nurse. Some specialist nurses stated that they do not have the time to case manage women with gynaecological cancers and leave it up to the woman to contact them if needed. One nurse felt that the difference between the women who called and those who didn't, related to coping mechanisms and complexity of disease and treatment.

Point of contact and assessment, referral and then that patient can contact you as they need to as the go-to person. You don't have to case manage them. –IP-06

… women have my contact details and the understanding that if they need me, they ring me because if I rang all of them, all I would do is sit on the phone all day and ring them all. IP-03

…you know some people don't need me at all and I never second guess… But I think early on [they should have contact with a specialist nurse] *so that they know that I'm there if need be… women having combined chemo-RT… I'm much more likely to see them and that's just because there's lots going on for them.* - IP-02

One participant discussed the need for specialist nurses to empower their patients to self-manage their care from the start of their cancer journey and encourage them to shift their focus from illness to wellness in survivorship. The same participant felt that reliance on the specialist nurse should be avoided and that although she believed access to a specialist nurse should always be there, a community-based model of follow-up was desirable.

…the most important aspect is being able to follow that person through their treatment, but also at this point in time, it's shifting this focus that they're having on illness to wellness, and starting that from the beginning. So I think that that's a very important role, so we're actually looking at more patient-centred care, but also supporting self-management from the very beginning. – IP-08

I believe that the access should always be there…I'm in two minds now with regard to the support that we can offer post treatment… we should also be encouraging and facilitating more community based care, and getting people to assimilate back into their community opposed to being reliant on the specialist service that is giving that care. – IP-08

Although most specialist nurses felt that being the patient's 'go-to person' was the most important aspect of their role, it was acknowledged that not all patients required or desired that level of care. An alternative view was offered by one nurse who believed that patients should be encouraged to self-manage their care.

'The patient's advocate'

The specialist nurses also viewed themselves as advocates for the patients, especially in the context of multidisciplinary team meetings. They stated that they represented the patient in these meetings, offering a perspective of their family and social circumstances that may otherwise not be considered in the formulation of a treatment plan. Some nurses also spoke of their chaperone-like role during physical examinations and on ward rounds, and the importance of providing support during what can be a confronting experience for women.

…these women are discussed in an MDT [multidisciplinary team meeting] *and… the gold standard would be to have radical surgery… but, if we're talking about… a lady who's got a whole other list of comorbidities as well attached to that, sometimes surgery isn't the option. That's not what they want. We may have met them earlier… sometimes [we're] the only ones… that's physically laid eyes on this lady apart from everyone else reading her details on a piece of paper… many a time we discuss things in an MDT with a lady who's got PV bleeding, known to have an endometrial cancer, but lives in a high level care hostel with dementia.* – IP-12

I'm perfectly comfortable to add to the discussion and say, "I know this lady she needs to have her care nearer to home. She refuses to come up here, or, she's absolutely refused to have chemotherapy" or whatever so we can, we can speak up there. - IP-06

… especially in those meetings you… advocate for patients that might not be able to come to [name of capital city]; they might be able to go somewhere else. And all those things are negotiated and I'm usually the one that thinks of those, not the doctors… - FG1-P01

One participant described it as 'what any nurse would do', but protecting the patient's dignity and privacy is an important aspect of the specialist nurses' role.

I see them at our new patient clinic; I always go and talk to them before they see the doctor… women do from time to time tell me how they're very frightened of examinations… because they might have been sexually abused or been in an aggressive relationship… - IP-01

When I do the team round, invariably, and any good nurse will… our patients can be quite vulnerable… just having a pelvic examination in the bed, on the ward, in front of eight people. You know, little things like that. – IP-04

The specialist nurse provided a 'voice' for the patient among the multidisciplinary team and they also ensure that their care is organised to best suit their clinical and personal needs. The specialist nurse often played the role of coordinator of the patient's care as described in the following theme 'The Coordinator'.

'The Coordinator'

Participants described their role as the coordinator of the patient's care. Some specialist nurses did however have a designated cancer care coordinator in their team who played this role for the patient, but most were responsible for the coordination of the patient's care. Care coordination involved many tasks for the specialist nurses including booking appointments, scheduling treatment, assisting with travel needs, making referrals, ensuring that the patient has attended the required tests and communicating the outcomes to all relevant parties. The specialist nurses emphasised that care coordination is particularly important when the patient receives their treatment at different geographical locations or when they live a considerable distance from health services.

… one of the main things that I do is make sure people are on track with their imaging, pathology and their follow up as well. So making sure they've had their scan and smears and stuff when they need it, and if they're abnormal, getting them back in to see whoever they need to see quickly, rather than waiting for a result to be sent to a doctor who then talks to a secretary who then books an appointment not knowing what the whole story is. – IP-05

So my role is everything from symptom management to educational support, information, liaising with other agencies, especially when we are sending patients to [name of city], and lots of complex communication and processes that go on with sending patients up to other [health services] – IP-10

One specialist nurse explained how their service had a large catchment area and patients could be coming from 4-6 hours away and may never have been to the city before. There was a need for her to ensure that all tests and appointments were scheduled on the same day for these patients to ease both the physical and financial burden on the patient.

You know, there are often people who've never come to [name of city] before, have no idea how to get around and so a lot of that is just trying to just smooth the way in. – FG2-P02

Being the patients' 'go-to' person – coordinating their care, advocating on their behalf and being a reliable source of information and expertise, was what the specialist nurses identified as the best part of the role. The theme 'A rewarding relationship for the specialist n nurse too' explores this further below.

'A rewarding relationship for the specialist nurse too'

Through the reflections of the specialist nurses it was evident that the relationships, often long-term, that they developed with the patients, were a rewarding aspect of their role. With some participants having been in their roles for many years, the specialist nurses recalled how well they had come to know the patients and their families and vice versa. When asked what they liked most about their job, most participants stated that it was their relationships and interactions with the patients and their families.

…we actually do know our patients really well and our patients I've known for… 15 years that are still coming through the service, because that's how long I've been there….It's not impersonal. It's very personal in that relationship that you develop with them… you see their kids grow up sometimes. – FG2-P02

I guess that I love working with women and supporting them through what is often a really time of great vulnerability. I like to empower them and give them back some control, so that they feel supported, and I guess that's the biggest buzz I get from it. I love working within the gynae onc team. - IP-03

…a lot of them are characters and I love the continuity… you get lots of feedback. I guess you get what you give… they seem to like me and I like them, you know. It's nice to get a hug or get told that you've done a good job. – IP-11

As the specialist nurses kept in contact with the patient beyond treatment, they were able to update ward staff on the progress on the patient.

… the other thing… that I really enjoy is that continuity of care, of meeting a patient you know at that first clinic and being part of that when they come back to clinic and being able to say when the nurses on the ward say, "What happened to Mrs so-and-so? Have you seen her lately? How's she going?" And being able to be that person that updates everybody else on what's happening with who. I love being that. – FG1-P02

Overall, the theme 'The patient's go-to person' provided insight into the role that the specialist nurse played for women with gynaecological cancers, from the specialist nurse's perspective. The specialist nurses see themselves as central figures in the women's experience of gynaecological cancer care, playing a unique role to other health professionals. Participants identified their ongoing accessibility, advocacy, knowledge and expertise as hallmarks of their role in relation to the patient. Although a close relationship

was not desired by all patients, specialist nurses credited the relationships that they formed with their patients as a source of reward in their work.

'When so much depends on one person'

The third major theme identified from the focus group and interview data was 'When so much depends on one person'. This theme relates to the central role that the specialist nurses report they play in both the treatment team and the patient's cancer journey. While the other major themes related to the positioning of the specialist nurse role in gynaecological oncology and the relationship that the specialist nurse has with the patient, this theme relates to the impact that these have on the specialist nurse – on their workload, fulfilment in their role and their overall wellbeing. Within this theme, perceptions of time, succession planning, growing workloads, the need for self-care and the 'mother-like' role that the specialist nurse plays within the team were all explored.

'An ever-expanding workload'

Many of the participants have held their role since its inception and discussed the challenges inherent in creating a nursing role from scratch without guidelines or precedent. Their roles had evolved over time and their workload continued to expand as both their patient cohort grew and responsibilities were added to their role. Several participants reported that their workload was untenable. A lack of funding and resources were cited as the reason for their large workloads.

The enormity of the role for some specialist nurses was well articulated by one participant who discussed how her role had evolved from managing multiple tumour streams but was then narrowed down to

gynaecological cancers and cancers of the central nervous system (CNS). Yet with the growth in patient numbers in these two cancer tumour streams, her workload had grown to the point that she was fulfilling two full-time roles.

So I took on gynaecological cancers and brain tumours which don't have any synergy at all… that was based on the numbers of referrals and the complexity in the workload at that time. Since then, both tumour streams have absolutely exploded, but I am still responsible for both. So that makes my job very difficult, because they're both now more than full time jobs being done by one person… that sense of if you haven't got it all done, and you walk out, and you get hit by a bus, nobody's going to be able to just pick up and run with it. You know every night when I leave work I send emails to myself while I'm on the way home, or when I get home, to remember to do things the next day –IP-05

The same specialist nurse expressed frustration at never having the time to develop her role as she was always too busy managing her current work.

I hate that I have to share two tumour streams…. it's almost impossible at the moment… I'm exhausted… I think all of us are probably feeling like we're just holding it together, and in my job I want to be proactive and I want to make assessments and I want to figure out a vision for this role. But I'm so busy doing the work, the role, that I can't find my way clear to do that. – IP-05

Another specialist nurse shared her experience of being the sole gynaecological oncology specialist nurse for an entire state, likening it to a well-known book and TV character. The nurse explained how challenging it was to keep the names and faces of so many patients in her head.

I often explain my role as like the fat controller with Thomas the Tank Engine… because there's only one of me for the state, as that person that everyone comes to… Sometimes I wish a little picture would come up [of the patient] because, you know, the numbers are so big even though it's small but there's only one brain and, you know, it's really hard but I often say I'm trying to control what's going on, and that's really challenging. FG2-P03

The lack of funding available to support the role was evident in the account of one specialist nurse who was paid at a lower pay scale than other specialist nurses in the study and routinely worked significant amounts of unpaid overtime. This participant also mentioned that her husband gets angry at the overtime that she works, signifying the personal impact of such a workload.

… whenever you go there [nursing administration] about extra hours or extra money for my position, they just say, "Well, there's no money in the pot." … I love the job but at the same time I do put in lots of extra hours of my own time… I've told my boss [gynaecological oncologist]… he said that he'll try and do something but… I've actually gone to the union now to see if they can help me with my case….You feel like… how can I do all these things that they want me to do…. I work 10 hour days on Tuesday, Wednesday and Friday… the only day that I work sort of six or seven is on a Monday and a Thursday and I make myself do that… because I only get paid for 30 hours… My husband gets really cross with me. – IP-11

This same specialist spoke of the need for her to fill service gaps such as that of a psychologist. Other participants relayed how many extra jobs get allocated to them and how patient administration was

particularly time consuming. Likewise, the patient's use of email to contact the specialist nurses has further increased the nurses' workload.

I think one of… the extra things that I seem to be doing more lately is emailing, patients emailing you as opposed to calling you…So that's certainly increased over the last couple of years where people want your email address and they'll send you questions via email. – FG1-P02

I say to the doctors I work with, "If we could have an anxiety clinic here… that's one of the biggest challenges that we face. And quite often people come in with, okay, physical symptoms but a lot of them are psychological as well… we don't have… psychologists. We don't have psycho oncology unfortunately. Only point one FTE or something… It's another underfunded area – IP-11

I've got to do all that myself too…identifying patients that I need to see, making appointments with people and all of that… if there was one thing I could change, it would be if… I didn't have to kind of make all those phone calls, initial contacts and make all those appointments and things. – IP-13

Just as the specialist nurses reported many small jobs being added to their workload, so too the specialist nurses took on significant aspects of what was traditionally doctors work through the institution of nurse-led clinics. Most of the nurse-led clinics followed-up low risk patients previously seen by medical staff, allowing them to focus on new patients and higher risk patients. The specialist nurses were however very positive about this expansion in their scope of practice.

… the fact that our unit was getting busier and how could we utilise my skill level in a way that can… improve the entire service as far as getting the women seen when they need to be seen, giving them the time to discuss things that they need to discuss that they often felt that doctors didn't

have the time to do. Something that was acceptable to the women to be seen by a nurse, and allowing the doctors to see the high risk and the urgent new patients and getting them through, and it was something that I put forward. – FG1-P02

My role I would like to see… more clinical. So running more of these clinics, and hopefully that will be established in the next six months. I foresee as the hospital is getting busier… the clinical nurse specialist's role sort of intermingling a bit with the registrar role. IP-10

Although some specialist nurses would like to run a nurse-led clinic in their department, their existing workload and lack of resources were prohibitive or the specialist nurse has refused to take the extra work on. With such demanding workloads, some nurses spoke of how they have learned to say 'no' and set boundaries on their workloads.

I've refused [to run a nurse-led clinic]. I want to, and if this was a gynae only role I would absolutely be pushing for that… our consultants in radiation and medical oncology, they said that would really free them up to do a lot more of the intense work with the new patients, and they would be able to see new patients much more easily. But I'm not prepared to take on any of that workload currently. - IP-05

… when the registrar comes up and says, "Can you arrange this?" "Well, you can pick up the phone just as well as I can and book that in," and some days I'll go, "No, this is the number to call. You go and do that. This is where we need to book it at. You're capable. I'm busy," and then other days when I've got a little bit more time I'll go, "Yeah sure," because maybe it's a patient I want to call anyway, and so I'm getting better at pushing back as I've gone on, and sometimes it depends on who your fellow is and things as well. - FG2-P02

When discussing their workload it was clear that many of the specialist nurses were working unpaid overtime to meet the demands of their role yet when it came to giving the patients 'time' they made themselves available, as explored in the following theme 'Dichotomies of time'.

'Dichotomies of time'

The specialist nurses spoke of giving their patients '*the time that they need*' even though they were clearly time poor themselves and that there was a perception among the patients and other team members that the specialist nurse had more time to spend with the patients. The accounts of the specialist nurses however showed that they did not have more time but gave their personal time to the patient. Some specialist nurses spoke of giving 'their' time to the role in the form of unpaid overtime though this clearly impacted their personal lives.

The infiltration of work on personal time was evident in the following account from one of the specialist nurses:

With my job because I come home on Friday nights… Mondays and Fridays are my worst days and on a Friday I'll often get home by eight-thirty of a night and I've started at half past seven in the morning, plus travel, and then I walk in. I have a wonderful husband, but I'll say, "Hello, I've just got to answer these few messages. I've just got to make a couple of - Okay, alright, I've just got to make this phone call," shut the door and run away very quietly and make this phone call because otherwise I don't shut down, you know, and you've only got Saturday and Sunday before it starts, and if I know - If I've looked on my phone and I see that message there, I have to deal with that before I can actually shut down and try and have some time – FG2-P03

During focus group two a discussion occurred between the participants about unpaid overtime that resulted in consensus that unpaid overtime was time that the specialist nurse gave to their role. If it was for the benefit of a patient, the specialist nurses were prepared to give the time needed even at the expense of their own personal time. A participant in focus group one discussed that one of the benefits of her nurse-led clinic was that the patients had time to discuss the things that they wanted to discuss, an opportunity they were not offered in the doctor's clinics. Yet the same nurse shared the following frustration regarding her time:

…time's always the big factor that I struggle with, getting stuff done, having enough time in the day, always working over my hours… [I] try to take time in lieu but that never happens. FG1-P02

Another nurse qualified that she sets herself boundaries and only works late if it's for a patient and not to complete administrative tasks.

I'm happy to do it but there are certain things I do to make sure that I don't do it every night of the week. So, you know, I schedule in my pilates and my exercise at a certain time and I've got to go because I'm booked in… if it's admin - no. – FG02-P02

Ironically, one participant's role was funded by reducing the medical fellow's overtime hours which were effectively replaced by the specialist nurse's unpaid overtime hours.

You know part of the reason why we did my role originally was that the fellow's hours were so out of control and they actually had to pay that person overtime hours, so some of the funding for my role actually originally came out of saying, "Okay, if we get the fellow's hours down we have this much

money to then spend on a nurse," but very quickly it got to the point that I was actually staying longer than the fellow. – FG2-P02

Similarly, another nurse explained how she worked long days but had no option to claim overtime despite her medical colleagues being able to do so.

And I work 11 hour days and I do emails at home on the weekend and when I'm at conference… I have no ability to claim overtime… I can get time in lieu but… my medical boss doesn't believe in time in lieu, "You're working at a higher level, you're expected to work these hours". –IP-04

Most specialist nurses reported that they worked regular overtime which was dichotomous to the perception of the patients' and team that the specialist nurse had more time to spend with the patient.

'The team mother'

Just as families are often reliant on a 'mother' figure who knows everything that needs to be done, so too the treatment team relied on their specialist nurse to organise them and ensure that nothing is missed. Likewise, the specialist nurses reported having the responsibility of '*growing up other nurses*' (IP-02), playing a role in mentoring and teaching other nursing staff. Some specialist nurses also acted as harmoniser in the team, accepting each member's eccentricities and playing the role of peacekeeper. The specialist nurse was the patient's central contact but they were also the central contact for the team and a conduit for information about a patient.

… I'm the contact person for the team, today one of the doctors contacted me today to see if I can find one of the other doctors to order an MRI … I'm the constant… I'm sort of the team mother

you know… I'm older and I'm like their mother… I'm the one that accepts everyone's foibles and their ways of being. You know, sometimes people in the team can be cross with each other – IP-02

The specialist nurses described themselves as a 'safety net', always double checking to ensure that others have completed their work and that nothing was missed for the patient.

We've got a bit of a staffing crisis with our medical team currently, so I'm finding more and more there are things that - paperwork that hasn't been done, which is halting the process on patients' journeys… I'm double checking and making sure that referrals are sent, patients are going up to their appointments in [name of city], are being told what their results are. – IP-10

A lot of the communication comes through me because it can take weeks for a letter to reach somebody and they'll need to be seen in the meantime or they'll need imaging in the meantime, and I'll get those results and give them to the appropriate person in their team. – IP-05

The specialist nurses took it upon themselves to ensure that the patients received timely and appropriate care.

But probably one of the main things that I do is make sure people are on track with their imaging, pathology and their follow up as well. So making sure they've had their scan and smears and stuff when they need it, and if they're abnormal getting them back in to see whoever they need to see quickly, rather than waiting for a result to be sent to a doctor who then talks to a secretary who then books an appointment not knowing what the whole story is. – IP-05

The doctors do a very good job, but we need to be there to actually make sure these people are getting to these appointments, and that actually things are getting organised for them, that it's appropriate for their care. Sometimes doctors… they sign things, but they don't actually double check that things have been done… -IP-07

The specialist nurses also played the role of mentor and teacher to nursing staff on the ward, imparting their knowledge with others.

I have a big responsibility in educating and teaching all the nursing staff, especially the ones who work in the ward who are new graduates … – IP-01

… I'm that constant source of information for junior staff... we've got lots of new young nurses coming through and I really enjoy having that relationship with those nurses, where they can come to me and say, "Hey FG1-P02, what do I do here?" – FG1-P02

Despite there being so much reliant upon them, the specialist nurses report that they have little to no succession planning in place and found it difficult to cover their leave as discussed in the following theme 'No one to fill the specialist nurse's shoes'.

'No one to fill the specialist nurse's shoes'

The specialist nurses spoke about the barriers that they faced in creating a succession plan for their role and in taking leave from their position. They saw that taking leave and succession planning were linked as leave cover was an opportunity to introduce others to the role, which may have lead to a succession plan.

However, most were not successful in securing regular cover for their leave periods which in some cases prohibited them from taking a break.

The specialist nurses found it difficult to generate interest in their role and attributed this to the hours that they worked and a lack of confidence on the part of others that they could fulfil the role.

…I'm having my leave in October and even just finding someone to fill my role for two weeks people are frightened of what it is my position does and don't think they can do it… The nurses on the ward think "I could never do what you do."… Certainly someone is going to step into my role but she's terrified – IP-09

There are no succession plans…. there's not a lot of people who are actually interested and the hours don't help. We wouldn't expect them to do it to that level, you know, but when they see me there late at night they go, "Why would I want to do that?" I don't see a way of really making it a - You know, what's the incentive, really, other than meeting some great women and doing a really worthwhile job? - FG2-P02

Often the cover that the participants had arranged for their leave was pulled into another area leaving the specialist feeling that they are unable to take leave. Some could only get cover for their leave for certain periods of time and without it would get someone to cover the bare minimum and have a bad week upon return trying to catch up.

As for … even leave cover, there is nothing… I've developed an orientation manual. But really that's just where are the clinics, when are the clinics… the person who was lined up to be my backfill

for this year has been pulled into the lung cancer care coordinator role. So I don't even feel like I can take leave at the moment. – IP-05

I had to take two weeks' holidays [to attend the conference] *because the person wouldn't get paid higher and wouldn't be interested in doing it if they didn't.* –FG2-P04

It always amazes me as well that the teams supply these roles right, and the roles, I guess, that we play for the patients and with they're - You know, they're quite important within the structures of the team and yet they aren't covered when you go on leave. -FG2-P05

… if it's only for a week or so I'll often not get covered… these three days the chemo coordinator is checking my messages and just handling any referrals and things that come in… they just keep things ticking over until I'm back and then you have a bad week while you catch up on everything. – FG2-P02

The demands that the role places on the specialist nurses indicate there is a clear need for professional support and self-care of the specialist nurses as considered in the following theme.

'The need for professional support and self-care'

With so much dependent on the individual in the gynaecological oncology specialist nurse role, there was a need for them to have access to professional support and engage in self-care. The professional support available to participants varied greatly and so too their feelings of being supported and being able to effectively manage the demands of their role. Some participants experienced high levels of work-related stress and burden in their role which affected their wellbeing. Those participants who had access to clinical

supervision seemed to feel better supported and more in control of their role. So too, those who had the support of nursing colleagues and remained close to a nursing team also reported camaraderie and opportunities to debrief as important strategies to manage work-related stress. Some participants mentioned the self-care strategies they used to manage the stress of their work.

Participants reported high levels of stress and anxiety in relation to their work and received little or no support within their workplace to manage this.

I'm dreaming a lot about work and I dream and wake up panicked, because of silly things like a blood group…but a host of other things that I dream. So I sleep. I work while I sleep as well and that's a new phenomenon for me… It's just a routine thing now. And some mornings I'll wake up and think, oh it's so exhausting it's like I'm at work all night. – IP-04

Encouraged by a family member, the participant went to her head of department but did not receive any support.

…he has no tolerance for people not being able to cope, so I was shut down instantly and it was, "You wanted this job, you deal with it. These are higher level nurses who have to accept this stress"… And I'm proud of being able to sort of get to the role that I wanted, but it's almost like be careful what you wish for because you might well get it... Now it's like, oh God, how long can I sustain it for? I can't sustain this for another 10 years. I can't, it's too full on – IP-04

Another specialist nurse reported that she was at the point of exhaustion. The team she worked within

were supportive with regards to clinical/medical issues, but they too were stressed and overworked. Although an employer funded assistance program was available to her she felt this was inadequate and opted to pay for a private psychologist to help manage work-related stress.

They [medical colleagues] are fantastic but equally overworked. I went to my GP and got myself a referral to a psychologist… I don't think the EAP [Employee Assistance Program] provides enough. – IP-05

One specialist nurse sourced and paid for her own clinical supervision for the first four to five years of her newly created role.

… it wasn't sourced by the employer, I sourced it myself, and paid for it myself. – IP-03

The specialist nurses who had clinical supervision in place or were close to a nursing team felt more supported than those who didn't. Ways of debriefing that are common to nursing culture such as the 'tea break' were helpful in generating a sense of camaraderie for the specialist nurses.

…the team is a small team, and even though that can sometimes pose difficulties as far as relationships with each other, I think we are… like family. I mean I've been in the role for 20 years and we've had some recent deaths within our small unit of staff and recent illnesses, and I think it really becomes, you know, we are each other's family, and having that support amongst each other. And even having you know the fellows that rotate through the service, seeing doctors that have been with us, as residents and registrars, coming back through the ranks. It's like it's bringing all the girls back home. - FG1-P02

We've got a really great team of nurses out on the ward so we often use, you know, tea breaks and things like that if we're really having a tough trot of patients who are coming through. – IP-12

I'm not burnt out because I have clinical supervision to help me to maintain my life balance. That's part of what comes with my job. You know [name of nurse], my director of nursing, had such a vision of how can nurses achieve this? We have clinical supervision. – IP-06

We have access to clinical supervision… through [the hospital]… we've brought someone in to do external supervision… and we can actually book in to have an appointment with him. And that can be a chance to debrief or get advice and work things through as well. – FG2-P06

One participant relayed her positive experience with clinical supervision in a previous role as a McGrath nurse but did not have such support in place in her current role as a gynaecological oncology specialist nurse.

… I thought I have nothing to say but as the months ticked on I actually got a lot of benefit from it and it was really quite amazing how good I felt. Doing this role, there's my supervision, "Oh, there's a 1300 number you can ring," but actually I'll get around to that. I really think I need to ring, but having that locked in time, "Actually, you're booked in for ten o'clock," "Oh, yeah, okay," but I actually found it really, really beneficial. FG2-P03

The need to have clinical supervision in place for specialist nurses in gynaecological oncology was highlighted by one focus group participant who worked in the role part time and was able to take somewhat of an outsiders view.

… what's lacking in the gynae-onc CNC world is like a model for support or supervision… I just know a number of people in these roles that are good friends and I have seen the toll that it has taken on all, absolutely every single one of them at different points where it has gotten absolutely too much… You know, a loss of any of any of the CNCs would be terrible for the services of those nurses working because you think about what it takes to build someone up to that point and the intimate knowings of what's going on with those patients and the hospital processes and all of that stuff, you could see how it could really effect patient care, and we don't want that to happen to the people that we care about in terms of our nursing team as well. - FG2-P05

Other specialist nurses highlighted the need for self-awareness and self-care to help manage the demands of the role.

I do things like yoga and I do relaxation. Yoga's just been wonderful to help me just to cope with everything. Like, sometimes when you think, you know, something's just too much - IP-11

It's certainly a lot of self-care that you need to do as well. Everybody needs their time out or their something. We have a very supportive nursing staff on this ward. I mean my office is often the debriefing place for people to come in just to scream… They can come in here and they know that they can air their grievances which is fine but then I also have the opportunity to do that as well. I think that's important to be able to have somewhere within the workplace that you can do that as well as having an outlet away from work as well or a hobby or some down time. I think you can take a lot of the role home and that can be quite difficult. – IP-09

The need for professional support and self-care was evident in the accounts of the specialist nurses in this study, from both those who had good supports in place and those experiencing high levels of work related stress.

Through the theme 'When so much depends on one person' it was evident that the gynaecological oncology team and patients with gynaecological cancers relied heavily on their specialist nurse. The specialist nurse played the role of central contact for both the team and patient which, for some nurses, created a busy and stressful job. Their ever-expanding workload saw specialist nurses routinely working unpaid overtime yet when a patient needed 'time' they willingly found it. There was a clear difference in the overall wellbeing of the specialist nurses who felt supported in their team or had access to clinical supervision to mitigate the effects of their demanding role.

'A clearer pathway'

Across the interviews and focus groups, participants reported the challenges experienced in setting up their roles and constantly evolving to meet the needs of their health service. The specialist nurses lacked a clear pathway to follow and, when asked about the future, they desired better defined role boundaries and distinct education and career pathways for gynaecological oncology specialist nurses. Likewise, the need to standardise the care provided by specialist nurses to women with gynaecological cancers was identified by several participants, though some qualified that this should not prohibit the provision of individualised care. The theme, 'A clearer pathway', was derived from three minor themes: 'Delineation of roles'; 'Identifiable career path'; and 'What *should* I be doing' and explored the specialist nurses' visions for the future.

'Delineation of roles'

Most participants reported that their roles were poorly defined or diverged from their official position descriptions. Some participants reported role overlap with other health professionals and though mostly managed well, it highlighted the inherent challenges for specialist nurses in having new and often poorly defined roles. The need to differentiate between advanced practice nursing roles was also evident in the accounts of the specialist nurses. Role overlap was experienced occasionally by some specialist nurses with various other health professionals from doctors to other specialist nurses though this was mostly resolved through good communication.

The responsibility of psychosocial care of the patient was difficult to determine for one specialist nurse where a psychologist was part of the team.

I'd say the other thing in relation to the team is the overlap we have… about where the role of psycho-social support sits… whose responsibility is it? I feel it's everybody's responsibility, that psycho-social care, but where does my role stop and [the psychologist's] role start? FG1-P02

When doctors in the team spent a lot of time educating patients regarding their treatment, the specialist nurse felt that there wasn't a need for them to then arrange another appointment to see them.

… it's a lot of time that they're in there with the doctor. Our doctors, anyway… with the radiation oncology doctors, a gynae patient could be in there for an hour… it's really hard to see that I can really be of much benefit to them after they've spent an hour with the doctor. – IP-13.

There was conjecture from some participants as to who should be responsible for the coordination of patient care and whether this needed to be a specialist nurse. Some specialist nurses coordinated care as part of their role, and their role title reflected this, while others worked in conjunction with a cancer care coordinator who may or may not have been a nurse.

When both a specialist nurse and care coordinator were included in the team, clear role definition was required.

There is an overlap, definitely there is an overlap… there needs to be really close communication… But we've got a pretty good set up. We've spent some time organising what's the best way to work between the two of us, and it works quite well. – IP-10

…the patients are asking for it [a care coordinator] *and we need to provide them with that. Whether it's a clinical nurse specialist or a coordinator I think is probably more of a grey area. There's definite areas where a clinical nurse specialist is required on the patient's journey, but there's also some phases where a registered nurse coordinator - which is the set up we have here is appropriate I think. So that's a bit of a grey area.* – IP-10

A discussion between the two participants in focus group one revealed that one worked alongside a cancer care coordinator who was a physiotherapist and the other worked with a cancer nurse coordinator who was also employed as a clinical nurse consultant.

…the cancer care coordinator who I have had… is a physio… she doesn't give nursing advice because she's not a nurse, but certainly she facilitates care… and if there's any issues she will

contact me and say, "Look, this lady's having a bit of a hissy fit, would you mind coming over and see her? Or do you want to come and look at a wound?" – FG1-P01

…all our care coordinators are employed as clinical nurse consultants, but now they're [hospital administration] taking a step back and saying, "Perhaps we, we're paying too much. Do we actually need them to be at that level? In fact, do we need them to be nurse? Could an admin person be a care coordinator, because what is actually their role?" I totally disagree… You definitely need nursing knowledge, because the questions that I think a care coordinator gets asked by patients and families, without that knowledge, you can't answer them. – FG1-P02.

Clear delineation of what is within the scope of practice of a specialist nurse compared with a nurse practitioner is also required. Two specialist nurses were qualified as nurse practitioners though one was employed as a 'cancer nurse specialist' and the other as a 'nurse coordinator' and paid as a level 2 nurse. The nurses were working autonomously within gynaecological cancer teams but no nurse practitioner roles were on offer in their organisations. Another participant felt that she was practicing at nurse practitioner level except for prescribing, but didn't think she'd have the support of her local health district for the role.

It's certainly been something that I've thought about for a long time here in my role because it's, you know, in a lot of ways, other than prescribing it's how I function. I've thought about going off and doing the master's in nurse practitioner course, but it's a concern about whether there'll be a position. The way I currently perform my role it's almost at that level.. I've just got to go to someone and say "Can you write a script for this?" and they're happy to do that because they know I have the knowledge to make that decision but I just don't have the number to write on the form which can be frustrating at

times… I think I'm still able to achieve what I need to achieve as a CNC. I don't really know that having the nurse practitioner title would really make much difference. – IP-09

I've studied to be a nurse practitioner… there's no jobs unfortunately. But at the same time the knowledge that you have, once you've got it you can't sort of undo it, can you? - IP-11

One specialist nurse expressed that there should be more delineation between the clinical nurse consultant and nurse practitioner roles.

I order tests all the time… we developed a protocol in relation to our preadmission clinic in order to make it legal… So I do that now for the nurse led clinic… I guess maybe then as nurse consultants, we need to start to say then, alright if they're [nurse practitioners] *going to see people working at a higher level, then we need to stop doing all of that… So maybe I won't do a nurse led clinic, you know, I won't make clinical decisions.* – IP-04

The experiences of gynaecological oncology specialist nurses support the need to better define and differentiate advanced practice nursing roles.

'Identifiable career path'

Through the interviews and focus groups specialist nurses communicated that there should be an identifiable career path for nurses working in gynaecological oncology. The specialist nurses cited two main barriers to the development of an identifiable career path: no clear education pathway or minimum

education requirements to prepare for gynaecological oncology specialist nurse roles; and disparate role titles and pay scales among gynaecological oncology specialist nurses. In turn, the lack of an identifiable career path made succession planning difficult and was perceived by specialist nurses as a barrier to other nurses aspiring to specialist roles.

As reported in the section 'Interview and focus group participant characteristics and current practices' the specialist nurses who participated in the interviews and focus groups held varying role titles. Although not explicitly asked, some specialist nurses revealed their pay scales which also varied among participants. Some participants were being paid at level 2 of their state nursing award, and whilst the awards differ between states, this was a significantly lower rate of remuneration than that received by other specialist nurses in the study. There was a call from some participants for the standardisation of nursing nomenclature and pay scales, particularly in regard to advanced practice roles. It was suggested that a national classification aligned with national nursing registration be put in place.

I'm designated a clinical nurse consultant and the girls at [name of hospital] are nurse coordinators but essentially we do the same job… but we have different names… out of this it would be really good if everyone is actually called the same thing, because essentially I think we probably all do very similar jobs. – FG2-P02

But even the classifications outside of a nurse coordinator, if you're looking at what a grade one, grade two, a grade three nurse means interstate is different. And maybe we need something, we've now got a national registration, maybe we need to look more to having a national classification... – IP-08

… my title is a gynae oncology nurse but everybody calls me the nurse coordinator– my job is the nurse coordinator but I don't get paid as one, I get paid as a level two so that's an ongoing issue and one that, we're… going to the union to get that improved… I'd love just to be recognised for what I do and – and be remunerated. – IP-11

During the interviews and focus groups, participants offered their opinions as to the minimum education and experience requirements required to prepare for a gynaecological oncology specialist nurse role. Most of the specialist nurses stated that post-graduate education, ideally Master's level, was the most suitable education preparation to fulfil a specialist nurse role. Likewise, most participants wished that there was a gynaecological oncology education module for nurses to complete given that most of them had gathered their skills and knowledge for the role piecemeal.

I think it's important to have the general cancer knowledge, um and that's certainly something that I try and encourage our junior nurses to do, at least do their Grad. Cert. in oncology nursing, because I think having that background and understanding of how it all progresses is very important. – FG1-P02

I passionately believe you have to have a Master's, I believe that and I think you need to have that broad - you need the skills that doing that qualification teaches you to use in your practice. – IP-03

I think working towards a Master's… should be the standard that we're setting… I think a Master's pushes you to that next level, you know, really questioning the care that we're providing… we need to be looking to do more research or questioning our care or collaborating with other people in the

teams and thinking a bit more creatively, and I think that's where a Master's takes you… I think that's probably where CNCs should be aiming for. – FG2-P05

Participants in both focus groups thought that gynaecological oncology nurses should be aiming for something similar to the minimum education requirements for breast care nurses which is four post-graduate units.

… it's a small population of nurses that work within that speciality field [gynaecological oncology], but it certainly does need something… the way that the breast care nurses model has gone I think is something that we can, we can really learn from. – FG1-P02

As gynaecological oncology is a small field with a small nursing population, it was recognised by the specialist nurses that the opportunity to complete a course in gynaecological oncology was not presently available.

When we did the position description for the job we did say a Master's was preferred… I think you'd want some postgraduate studies in a cancer field… it's just limited in the gynae specific education out there… You know, my Master's was not really about my job at all, other than working in an advanced practice role as a generic thing. - FG2 – P02

… if you start [a Master's degree] with a view to being a gynae-onc clinical specialist you probably could pull various papers and put them together and come up with a really nice well rounded degree. – IP-02

One nurse who had not completed post-graduate studies and held her role based on experience felt that the role would need to be developed further in order to justify completing the extra education.

… at the moment I am capable of doing this role without those further studies, so it almost loops back into the role needs to be developed for the education to matter… if I was going to go and do some additional training and post grad studies… I think the role would need to be taken to that level where that's reflected. – IP-12

One interview participant suggested that a fellowship after completion of a master's would offer specialist nurses the opportunity to develop their clinical skills in a new role.

… an internship approach I think would be great… so you're actually paid and you go along and you're acting as a nurse in a speciality area. – IP-08

As explored through the theme 'No one to fill the specialist nurses' shoes', most specialist nurses did not have a succession plan in place for their role. Although most participants cited a lack of time as the major barrier to instituting a succession plan, a lack of a clear career and education pathway for nurses working in gynaecological oncology was also linked to a lack of succession planning. The specialist nurses closer to retirement were more advanced in their thoughts about succession planning with a focus on the experience and education preparation they believed were required to fulfil the role.

I've been looking at succession planning, and I've been saying, "Well you know if we start training a new nurse who has no oncology, I want to her to do six months in palliative care. I want her to do six months in oncology so she has got that as well as gynae, because it's important."… you can't just be

a gynae nurse and you can't just be an oncology nurse, you need to have a variety of skills, so I think it's critical that you have clinical experience as well as educational preparation. – IP-03

One specialist nurse pointed out that a lack of a clear education pathway and lack of confidence were barriers to other nurses becoming interested in and preparing to succeed these roles.

I think that's why it's difficult to – you know a lot of us who've been in the roles have been in there for quite some time and it's hard to get other people into the role because there's not really that clear pathway of where do you go to get your next level of education. There's experience from being on the ward and in the units but do you just do a cancer certificate, you know a graduate certificate in cancer nursing, nothing specific for gynae oncology? I think that's why people find it very hard to then have succession planning… - IP - 09

… I think they don't think they have the knowledge. Certainly they don't have the years of experience but they're dealing with these patients as in-patients on the ward on a daily basis so they do have the background knowledge it's just I think a lot of it is believing in themselves. – IP-09

Another specialist nurse believed that pathways needed to be created for their successors and that the role needed to be esteemed by nursing to make it attractive to others.

…so I think we need to be thinking about who is the future workforce going to be, creating those pathways, valuing and celebrating the CNCs and the jobs that they do because I don't think that we celebrate ourselves enough and each other, and creating that as something that is desirable and upheld as something to aspire to. – FG2-P05

The theme 'Identifiable career path' explored the specialist nurses' views on how the lack of a clear education pathway or standardised nursing career structure is a barrier to other nurses aspiring to and succeeding these roles.

'What should I be doing?'

As most specialist nurses had created their roles from scratch to meet the needs of their employing organisation, and without formal guidelines, many were interested in the development of guidelines for the role. As their roles continued to evolve, some specialist nurses were also considering how they may further extend their practice via nurse-led clinics. Through the accounts of those operating nurse-led clinics it was evident that there was a need for guidelines in regard to scope of practice in these clinics also.

Specialist nurses were asked to share their thoughts on standardisation of their role and if they thought that a document such as practice guidelines or a model of care would be beneficial to them. Most participants believed that such documents would be useful in ensuring that practice was uniform among specialist nurses. However, some participants did emphasise that any guidelines or models of care should still allow for the provision of individualised care and be adaptable to meet service provider needs.

Because for someone who is not from clinics and not from liaising work - I'm from the ward where it's all really structured… to come to this job… It's sometimes just kind of going, what should I be doing … it's very hard to actually pin down for me personally... It's not actually got a direction. – IP-07

I personally believe that models of care documents and guidelines are a solid piece of information to have. But my difficulty with guidelines is that it's always perceived as a guideline, it's not necessary that you need to implement that, so people have their own interpretation. I'm wondering whether we could go to something that's a bit more robust, that these are essential elements, opposed to just a guideline. – IP-08

I think if we want to have that professional standard it would give us…something to take to our organisations to say, "This is important. You know we've come together, we've agreed that this is - we've scoped through what is happening in Australia and New Zealand and there's a standard of care we should be providing women and to do that these are the resources we need, and this is the training we need, and this is the protected professional development time and the supervision and the connections that we need to have within our gynaeoncology team and internationally." FG2-P05

Whilst there certainly is the mention in them [optimal care pathways] that specialist nurses are part of the multidisciplinary team in gynae cancers, it doesn't really specify what it is that specialist nurse should be doing… I do think it needs to be taken to another level… the difficult thing would be consensus across the country. FG1-P02

Some nurses however specified that any 'guidelines' would have to be flexible enough to meet the needs of health services and individual patients.

I suppose the one big thing is that the roles are really different from place to place. Not even just state to state but from hospital to hospital and the plan would be in the future to somehow make a standard gynae oncology role. I think given the fact that the hospitals are so different… makes the role extremely different and I suppose roles have been adapted to each hospital, to what each service required

at the time. Very hard to make a standardised role. I suppose it could be standardised knowledge that could go with the roles but clinically how they operate I think that would be extremely difficult. - IP-09

So each tumour group has a standard of care and that pretty much outlines there so 'patients will be contacted by a nurse specialist within x number of days of their diagnosis'… we are documented as important… [but] individualised approach is important… and I think it's that ability to flexible that makes us valuable. – IP-02

The paucity of formal guidelines to direct the practice of the specialist nurses was evident in their discussion of nurse-led clinics. Participants discussed how it was up to the surgeons to decide their scope of practice within the clinics but also wanted formal documentation in place for professional protection.

…when I was asked, I was told, they'd agreed I could do this clinic, the follow up one, I then said, "Okay, well we all need to sit down and I want guidelines. I want some sort of scope of my practice, because I tell you, if I don't have that, nursing will tear me to shreds". "Oh, bloody nursing". That was the comment [from the gynaecological oncologist] "Bloody nursing". And I said, "No, but it's actually, but I need it too because I need to know exactly your expectation of what you want me to do for these patients". I said, "I know what you all do, but I need it in writing. Nurses work by guidelines, by protocols and guidelines. That's how we work". - IP-04

I'm in the process of trying to set up a nurse led follow up clinic. So at the moment all of this is very ad hoc over the telephone, tagged on to existing appointments that they have here at the hospital… I'm discussing with the gynae consultant at the moment whether it's appropriate for me to do manual examinations. I know it's within my sphere of practice as a CNS… but I'm just thinking with these

highly risky patients, whether it's safe for me…I think it would be in house training, I would have to do a considerable amount of time, and I'm not sure that's going to be acceptable to the patients either. – IP-10

… so we've started a draft looking at how my clinic can evolve… a high risk clinic for patients with high needs… currently just seeing those 1A endometrial, I think that could probably be extended into other cancers… it's about getting the surgeons to be happy with what the expectation of a nurse's role in that follow-up would be – FG-P02

Specialist nurses wished to have guidelines in place specifying their role in the care of women with gynaecological cancers. In the absence of such guidelines participants looked to the surgeons within their team to stipulate their scope of practice or simply tailored their role to meet the needs of their employing organisation or individual patients.

The theme 'A clearer pathway' explored the specialist nurses' ambitions for the future of their role. They desired well-defined roles with clear boundaries that were differentiated from other advanced practice nursing roles. Based on their own 'piecemeal' education preparation for their roles, there was general consensus across the interviews and focus groups that any successors to their role should hold a post-graduate qualification, preferably a Master's degree. Yet the participants also conceded that although a gynaecological-oncology specific post-graduate qualification would be the ultimate preparation for the role, such a qualification was not available currently. Just as there was not a clear education pathway to prepare for a specialist nursing role in gynaecological oncology, so too there was not a clear pathway within current nursing career structures. Participants believed that the lack of a clear career and educational pathway to a specialist nurse role in gynaecological oncology was a barrier to other nurses

aspiring to and preparing to succeed these roles. The absence of guidelines to direct specialist nursing practice in gynaecological oncology had made the development of the participants' roles difficult. Generally the specialist nurses felt that guidelines for practice would be of benefit to them, though some stipulated that they should be flexible enough to enable the provision of individualised care and meet the needs of service providers.

Chapter 6 Summary

This chapter has presented the results of an analysis of the interview and focus group data collected from gynaecological oncology specialist nurses working in Australia and New Zealand. A total of 19 individual specialist nurses contributed to 13 interviews and two focus groups. Participants in the interviews and focus groups came from all states, territories and regions of Australia and New Zealand where gynaecological cancer services were offered. The specialist nurses participating in this part of the study held varying role titles and provided care to patients at different points along the disease trajectory. Eight of the specialist nurses were involved in nurse-led clinics. Fourteen of the interview and focus group participants either held, or were working towards, a post-graduate qualification.

A thematic analysis revealed that specialist nurses in gynaecological oncology 'work between worlds', the worlds of nursing and medicine and the worlds of gynaecology and oncology. In some cases, this led to their perceived estrangement from the discipline of nursing within their organisations and a lack of clear boundaries in relation to their scope of practice. Their role continued to evolve though they experienced mixed support for the advancement of their practice. The specialist nurses felt respected by the medical teams they worked within and saw their role as central to the functioning of the team, yet experienced

difficulty in maintaining their remit as nurses when working within a medical team. Many of the specialist nurses in this study were trailblazers and had evolved their role from one of 'physician's assistant' to an advanced practice nursing role. The specialist nurses identified strongly with their responsibility as the patient's 'go-to' person playing the role of advocate, interpreter and expert. The high level of accessibility the specialist nurses offered to patients on an ongoing basis was the hallmark of their role for some participants, yet others qualified that their services were not needed by all patients and that dependence on the role should be discouraged. The effects of playing such an integral role in both the treatment team and for the patient were evident through the theme 'when so much depends on one person'. Some specialist nurses shared their experiences of ever-expanding workloads, unpaid overtime and the burden of reliance on their role. The need for professional support and clinical supervision was identified.

The theme 'A clearer pathway' explored the specialist nurses' ambitions for the future of their role. There was disparity in the nomenclature and pay scales of the specialist nurses involved in this study and participants identified a need for greater delineation of advanced practice nursing roles. Specialist nurses were largely in favour of the development of clear education and career pathways for gynaecological oncology specialist nurses and the majority of participants thought that a Master's degree was the most appropriate level of education for a specialist nurse. Participants identified the potential usefulness of practice guidelines for the role but stipulated that such a document should not preclude the provision of individualised care. The specialist nurses felt that this, along with standardisation of nursing nomenclature and pay scales and clear education pathways would enhance interest in the role and aid succession planning. Overall, this chapter presented the specialist nurses' experiences and perceptions of their role and provided further insight into the similarities and differences between the way the role is practiced across Australia and New Zealand.

Chapter 7 – Interpretation and discussion

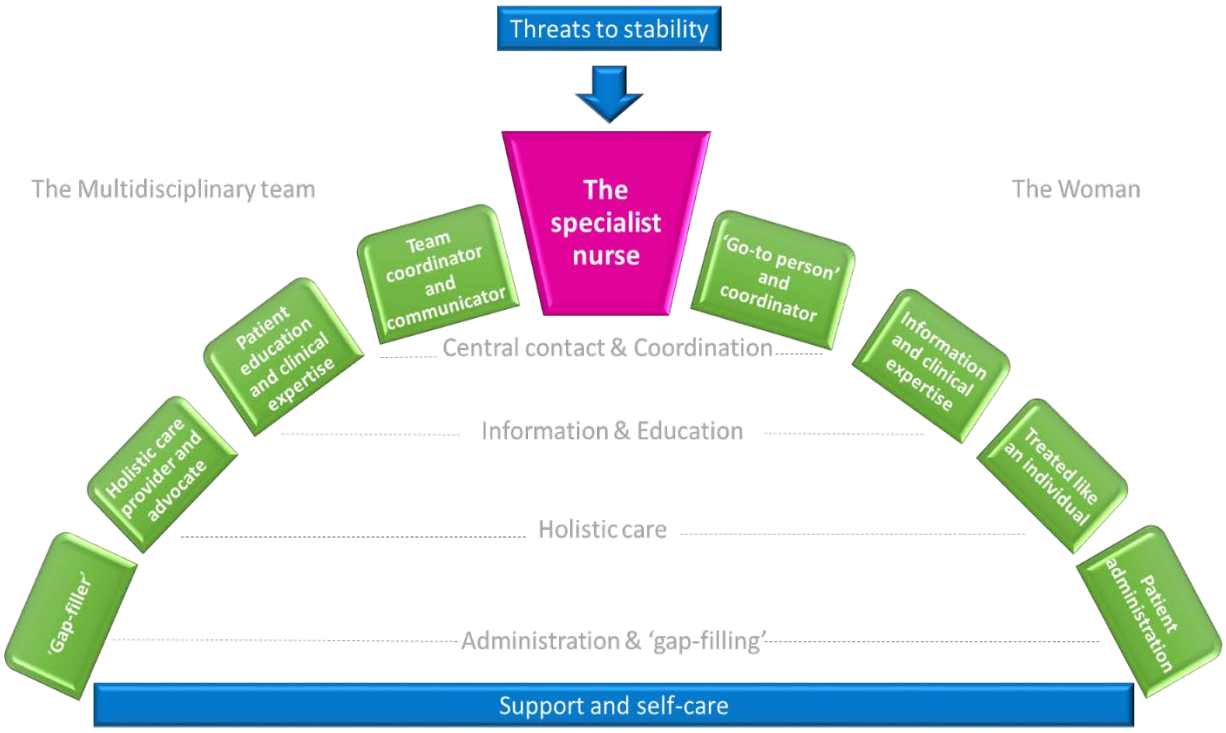
The overall aim of this study was to describe and define the specialist nurse role in the provision of gynaecological cancer care in Australia and New Zealand. Despite advances in the prevention of cervical cancer, the incidence and burden of gynaecological cancers continues to rise worldwide. Although comprehensive treatment of gynaecological cancers is available to most women in Australia and New Zealand, survival rates for women with ovarian cancer in Australia and New Zealand remain significantly lower than average cancer survival rates in the two countries. There is no early detection test available for ovarian cancer and the disease is often diagnosed in its late stages with a poor prognosis. Through the integrative review in Chapter 3, women with gynaecological cancers were found to have many needs relating to the delivery and coordination of their care, and the management of their symptoms and side effects. This study identified that the work of specialist nurses is focussed on meeting the supportive care needs of women with gynaecological cancers. Through an online survey, individual interviews, and focus groups, the experiences and perceptions of key stakeholders in the gynaecological oncology specialist nurse role were gathered, providing new insights into this under-researched role. The specialist nurse plays key roles in providing expert care to women with gynaecological cancers, organising the multidisciplinary team, and communicating within and between their organisation and other health services.

The specialist nurse as the 'keystone' of gynaecological cancer care

Many of the specialist nurses who participated in this study were the 'keystone' of their gynaecological oncology service, supporting both the multidisciplinary team and the women in their care. According to the Macmillan Dictionary (2018), a keystone is "the stone at the top of an arch that keeps the structure

together". If the keystone is removed the structure will collapse. Figure 7.1 depicts the specialist nurse role as central to both the multidisciplinary team and the patient in the provision of gynaecological cancer care. The other 'stones' in the arch represent the key roles that the specialist nurse plays within the multidisciplinary team and for the patient. Each stone on the 'multidisciplinary team side' of the arch corresponds with a stone on the 'woman's side' of the arch to form a major function of the specialist nurse role, discussed in detail below.

Figure 7.1 The specialist nurse as the 'keystone' of gynaecological cancer care



Central contact

There was consensus among both specialist nurses and treatment team members in this study that a key aspect of the specialist nurse role was that of 'central contact' for women with gynaecological cancers. The theme 'The patient's go-to person' explored the central role that the specialist nurse held in the

women's care. This was supported by the findings of both the systematic and integrative reviews where women valued having easy access to a specialist nurse who knew them well (Cook et al., 2017), and identified having a central point of contact as a need across the trajectory of disease. The need for a central contact within the health care team is not unique to women with gynaecological cancers however, and has been identified as an important aspect of care in numerous studies for patients with both gynaecological and other types of cancer (Fincham, Copp, Caldwell, Jones, & Tookman, 2005; Freijser, Naccarella, McKenzie, & Krishnasamy, 2015; Kobleder, Mayer, Gehrig, & Senn, 2017; Luck, Chok, Scott, & Wilkes, 2017; Monas, Toren, Uziely, & Chinitz, 2017; Salander, Isaksson, Granström, & Laurell, 2016; Tarrant, Sinfield, Agarwal, & Baker, 2008; Walsh et al., 2011). 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; Kobleder et al., 2017; Walsh et al., 2011).

Salander et al. (2016) explored this aspect of the specialist nurse role further by investigating the reasons for which head and neck cancer patients contacted their specialist nurse. The common reasons for patients contacting the specialist nurse in the study were for practical matters such as sick certificates and appointment changes, information about their treatment plan, or medical information. However, as was the case for some specialist nurses in this study, they found that some patients would contact the specialist nurse simply to check-in with them and report on their current situation. Salander et al. (2016) suggested that having a specialist nurse as a central point of contact went beyond fulfilling a practical need for the patient. This aspect of the specialist nurse's role was explored using attachment theory. Applying this theory, the nurse became an object of attachment for the patient (Salander et al., 2016). Attachment theory, first proposed by John Bowlby, relates to a child's sense of security that develops

when a caregiver is available and responsive to the child's needs (Harris & White, 2013). Eagle (2017) explores the transferability of Bowlby's theory to adults in clinical practice, suggesting that adults may form an attachment to their therapist or, in this case, specialist nurse, when a secure and safe base has been established (Eagle, 2017). When an adult feels trust and confidence in the availability of their attachment figure, they will share their problems and seek support from them (Eagle, 2017).

The role of central contact thus extends beyond meeting a practical need for the woman with the specialist nurse offering them a secure base from which to navigate their cancer journey. The role of central contact is also fundamental to the specialist nurse's role as coordinator of both the woman's care and the multidisciplinary team.

Coordination

Coordination was identified by participants of this study as a key aspect of the specialist nurse's role. This encompassed both coordinating the care of individual patients and coordinating the multidisciplinary team, as noted on both sides of the 'arch' in Figure 7.1. The treatment of gynaecological cancers is often multi-modal, involving several medical specialists and departments within a health care setting and often traversing more than one setting. 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, Fallon-Ferguson, and Koczwara (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). Although their job title may not have included the word 'coordinator', many specialist nurses and treatment 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.

Freijser et al. (2015) identified three levels at which a care coordinator operates within the system: the individual level; the service/team level; and the systems level. The Clinical Oncology Society of Australia's (Clinical Oncology Society of Australia, 2015) position statement on cancer care coordinators specifies that at the individual level, coordination should encompass facilitation of care delivery and ensure timely and appropriate referral to specialist, allied health and support services. Several other studies verify the importance of care coordination for cancer patients at the individual level (Luck et al., 2017; Monas et al., 2017; Tarrant et al., 2008; Walsh et al., 2011). The integrative review included in Chapter 3 found that 'the need to know that their doctors were talking to each other to coordinate their care' was a highly endorsed need of women with a gynaecological cancer. The perspectives of the specialist nurses and multidisciplinary team members in this study indicated that it was the specialist nurse who facilitated this communication between doctors. Specialist nurses were largely responsible for the coordination of care within the team and between services - coordination at the 'team and services level'. In many cases the specialist nurses provided leadership, support and coordination for the multidisciplinary team – a role referred to as 'The team mother' by one participant.

Should this study have been conducted through a feminist lens (Hesse-Biber & Griffin, 2015), the resemblance of the specialist nurse role to that of a mother could have been explore in greater detail. When considered alongside the proposition that the specialist nurse may become an attachment figure for some patients, the likeness between the specialist nurse's role and that of a mother is even more aligned. Feminist research is concerned with identifying and exploring how gender and a gendered social order impact women's lives and experiences (Polit & Beck, 2010). Whilst all of the interview and focus group participants were female, the gender of survey participants was not collected, and the impact of gender on the experiences of both the women with gynaecological cancers and the specialist nurses caring for them could not be investigated.

However, the coordination role that the specialist nurse plays at the team level may best be considered in this study with regard to 'relational coordination theory' (Gittell, 2000). Relational coordination is the process of "coordinating work through relationships of shared goals, shared knowledge and mutual respect" (Gittell, 2000, p. 518).The relationship between inter-professional relational coordination and oncology patients' perception of care was investigated in a study by Azar et al. (2017). Azar et al. (2017) found that the relational coordination indices of the nurse coordinators within oncology teams were the strongest and most positively correlated with patient perceptions of their care compared to medical oncologists. Azar et al. (2017) and Freijser et al. (2015) identified nurse coordinators as 'boundary spanners' within the context of relational coordination theory. They performed critically placed roles that bridge communication and integrate team functioning across roles within a team. Freijser et al. (2015) described coordination duties at the 'systems level' through involvement in policy making and development of referral pathways. Some specialist nurses in this study reported involvement at the 'systems level' of their organisation. The need for coordination at all levels is essential to ensuring the

best patient outcomes and several specialist nurse participants in this study were involved in all levels of coordination.

Information and Education

Linked closely to care coordination, the provision of education and information to the patient was identified as a key aspect of the specialist nurse role from the perspective of both patients and the team. Specialist nurses in this study reported that they played the role of 'interpreter' for patients, providing information and education in a language that could be understood by the patient. The integrative review included in Chapter 3 found that women wanted information delivered in a way that they could understand. Other members of the treatment team believed that the specialist nurse had more time to spend with woman to explain and reiterate the information provided to them by their medical specialists. The integrative review also found that whilst informational needs were prominent around the time of diagnosis and treatment, these needs continued into survivorship for women with gynaecological cancers.

A review by Koutsopoulou, Papathanassoglou, Katapodi, and Patiraki (2010), considering nurses as information providers to cancer patients, found that specialist nurses were very effective information providers and that patients preferred nurses as providers of specific information such as on symptom management. Other studies have shown that specialist nurses are important providers of information and education to cancer patients (Bishaw & Coyne, 2015; Tarrant et al., 2008; Walsh et al., 2011) and those with access to a specialist nurse received significantly more information and education than patients without such support (Guldhav, Jepsen, Ytrehus, & Grov, 2017). The provision of information to patients is thus a key support offered by specialist nurses, meeting the needs of both women and the

multidisciplinary team. The specialist nurses' patient-centred approach to meeting the informational needs of women with gynaecological cancers and their families is demonstrative of their overall holistic approach to care.

Holistic care

The provision of holistic care was perceived by treatment team members in this study as the domain of the specialist nurse. They believed that women were more comfortable discussing intimate and sensitive topics with the specialist nurse and perceived that the specialist nurse had 'more time' to provide supportive care and establish a therapeutic relationship with the patient. This was further supported in studies of patients with other cancer types (Moore et al., 2006; Tarrant et al., 2008). The specialist nurses in this study were focused on providing patient-centred care and reported achieving this both formally, through the use of assessment and screening tools and referral where needed, and informally through the close relationship they developed with their patients.

From the patients' perspective, the systematic review found that women with gynaecological cancers valued the extra time and individualised care offered by their specialist nurse which facilitated a deeper understanding of their needs (Cook et al., 2017). Women with gynaecological cancers wanted to be treated as individuals and for their interactions with the health care team to not be solely focussed on the presence or absence of disease. This was identified in the integrative review included in Chapter 3 and supported by studies of patients with other cancers (Bishaw & Coyne, 2015; Tarrant et al., 2008).

Specialist nurses in this study reflected on the mutually satisfying relationships that they had developed with patients and their families over the years yet conceded that providing this level of care was often emotionally taxing and sometimes required them to work unpaid overtime to provide 'time' to the patient. For the specialist nurses who conducted nurse-led clinics in place of medical follow-up aimed primarily at detecting disease recurrence, there was the belief that they were providing a 'value-added' service. The specialist nurses believed that they not only detected the presence or absence of disease recurrence through their clinics but also provided supportive care in the form of assessment and referral, lifestyle advice, education and information and symptom and side-effect management.

Similar to the results of this study, a study of specialist nurses who provided nurse-led follow-up to lung cancer patients found that there was concern from doctors that this level of care would "open the floodgates" and lead patients to share and seek assistance with their problems (Moore et al. 2006, p. 372). Indeed, patients in that study who were deemed to be well by the doctors reported more symptoms, psychological problems and functional difficulties when assessed by the specialist nurse (Moore et al., 2006). However, despite this and the resultant emotional burden for the specialist nurses, they believed that the nurse-led model of care provided supportive, patient-focused care with great benefits for patients (Moore et al., 2006). The specialist nurses in this study reported developing close relationships with the women they cared for. They believed this resulted in a deeper understanding of the women's needs that allowed the specialist nurses to act as the patients' advocate within the multidisciplinary team. It was acknowledged by treatment team participants in this study that the specialist nurse was the woman's representative in a multidisciplinary team meeting, ensuring that appropriate, patient-centred decisions were made regarding the treatment plan.

Whilst the provision of holistic care allowed for a greater understanding of the women's needs, this often translated to the specialist nurses' performing various non-nursing duties to ensure that women's needs were met.

Administration and 'gap-filling'

In their role as 'keystone', specialist nurses also fulfilled many administrative and ad hoc duties for both the patients and the multidisciplinary team. Likewise, their clinical expertise and 'system' knowledge were tapped into by both patients and other members of the multidisciplinary team. This was evident in their informal role fostering the skill development of junior doctors, reported by both the specialist nurses and the medical specialists, who relied on the specialist nurses to ensure the quality and safety of their service. The delegation of follow-up of some groups of gynaecological cancer patients to nurse-led clinics was evidence that the specialist nurses were trusted by their medical colleagues. Yet despite the acknowledgement of their advanced skills and knowledge, most specialist nurses also reported spending much of their time filling service gaps. One radiation oncologist participating in this study noted that their specialist nurse was burdened with administrative duties and compensated for deficiencies in other services such as social work. One specialist nurse in this study referred to these additional tasks as 'Bob-a-jobs' and another felt like a 'glorified ward clerk' when reflecting on the numerous menial and administrative tasks that fall to the specialist nurses in the absence of anyone else to do them. Specialist nurses performed these tasks for both the patients, and within the team, and were a source of frustration given they consumed time that could be otherwise devoted to nursing practice. 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. This was not a reality for many of the specialist nurse participants in this study. Yet, some participants

were not sure that all administrative duties could be delegated, given that an intimate knowledge of the treatment plan and patient themselves was often needed to plan and schedule care. However, specialist nurses in this study who had administrative support acknowledged how it reduced their workload and allowed them to focus on the clinical aspects of patient care.

The 'keystone' model of care discussed here relates to the functions of the specialist nurse role for which there was consensus among participants in this study. There were however differences in the way the specialist nurse role was executed between participants and organisations.

Differences in role execution

Whilst there was consensus between data sources on the role that specialist nurses played for patients and within the multidisciplinary team, there were differences in the execution of the role between participants and organisations. Differences existed in the points on the trajectory of disease when each specialist nurse was involved in care, the role titles and pay scales of the specialist nurses, the qualifications held by specialist nurses, their reporting lines, their responsibility for care coordination, operation of nurse-led clinics and the scope of practice within these.

Specialist nurse involvement across disease trajectory

Although the majority of treatment team members believed that it was 'very important' or 'extremely important' at all stages along the disease trajectory for a specialist nurse to be involved in the care of women with gynaecological cancers, only 15 per cent (n=5) of specialist nurses surveyed in this study and

26 per cent (n=5) of interview and focus group participants were involved at all stages. Some interview participants indicated that more than one specialist nurse was involved in the care of women with gynaecological cancers in their service, for example a surgical gynaecological oncology specialist nurse would 'handover' to a 'gynaecological oncology specialist nurse' once discharged from hospital following surgery. The common reasons cited for this arrangement were that surgical and adjuvant treatment were provided at different sites or that high patient volumes through the service required more than one specialist nurse. Some interview and focus group participants stated that they were not involved in women's care during adjuvant therapy, indicating that the chemotherapy and radiotherapy nurses were responsible for women's needs during this period. Only around one third of specialist nurse participants provided care in the pre-diagnostic/pre-admission stage. This stage is characterised by high informational, psychological and practical needs, as identified by the integrative review in Chapter 3 and may be a point where specialist nursing care could be effective. High informational and emotional needs were also reported during the pre-diagnostic phase in other studies of lung cancer and colorectal cancer patients (Wiljer et al., 2012; Wiljer et al., 2013). Whilst the literature indicates that patients prefer one point of contact across their disease trajectory, this may not be practical in some services. The results of this study indicate that it would be of benefit to women with a gynaecological cancer to have access to 'a' specialist nurse, ideally the same specialist nurse, at all stages along the disease trajectory, and health services should commit to meeting this need.

Nomenclature, reporting lines and education

As postulated in the background of this study, specialist nurses were found to be practising under different role titles, held different qualifications and reported to nursing managers at different levels within their organisation. The exception to this were the New Zealand specialist nurses who all held the same role

title, reported to the same level of nursing manager and held a post-graduate qualification. This highlights the fragmented and inconsistent nursing nomenclature between the states and territories of Australia and the impact that it has on career development and progression. Following on from the introduction of national nursing registration in Australia, Duffield, Gardner, Chang, Fry, and Stasa (2011) implored the nursing profession to also take a national approach to the standardisation of nursing nomenclature. Rather than being left to the organisations employing nurses, they recommend that the nursing profession decide on what the specialistions of nursing should be in Australia, and decree what the skills, knowledge and educational preparation for each were (Duffield et al., 2011). Duffield et al. (2011) identified the consequences of the development of new and highly specialised roles as 'role proliferation', 'role blurring', and 'role confusion'. These phenomena were all identifiable in this study. The reporting of more than 10 differing specialist nurse role titles in this study is indicative of the 'role proliferation' postulated by Duffield et al. (2011), where a diversity of role titles existed with little variation in the overall function of the roles. As Duffield et al. (2011) suggests, such proliferation leads to weak role identity, and 'role blurring' and 'role confusion' occurs when consumers, other health care professionals, and nurses themselves, are not clear on the boundaries of the role, which was the case in this study.

Of notable absence from the Australian nursing profession is 'role legitimacy' of specialist and advanced practice nurse roles. In a model proposed by Brown (1998) for advanced practice nursing in the US, 'role legitimacy' was a prerequisite for advanced nursing roles which required competency standards, a specified level of educational preparation, certification by a professional nursing body, and licensure in an advanced nursing category. With the exception of the nurse practitioner role, the nursing profession in Australia has not provided any of these prerequisites to nurses practising in other specialist and advanced practice roles. In their visions for the future, many of the specialist nurses in this study desired identifiable

career and education pathways and credentialing for specialist nurses that would 'legitimise' their role. The specialist nurses in this study believed this would aid in succession planning and overall recognition and support of their role. It could be speculated that the competency standards and minimum education requirements put in place for specialist breast nurses well over a decade ago, afforded them a legitimacy within society that has attracted enormous philanthropic support.

Nurse-led clinics and level of practice

The provision of nurse-led clinics by participants in this study was another area of difference in practice between the specialist nurses. Variation was found in the number of specialist nurses operating nurse-led clinics and their scope of practice within these. Some specialist nurses had policies and procedures in place to guide their practice within nurse-led clinics and others did not. Those without such guidelines and protection in their practice expressed a desire for standard guidelines for nurse-led clinics to be created.

The experience of Australian and New Zealand specialist nurses operating nurse-led clinics was similar to those in the UK. A large proportion of UK CNSs had taken on traditional medical responsibilities and relied upon in-house training or the 'shadowing' of senior doctors to develop the clinical skills required to do this (Farrell, Molassiotis, Beaver, & Heaven, 2011). As for some of the specialist nurses in this study, many UK specialist nurses conducted clinical examinations, ordered and interpreted blood and radiologic tests, and assessed for relapse in their clinics (Farrell et al., 2011). Australian and New Zealand specialist nurses in this study reported operating their nurse-led clinics parallel to medical clinics to ensure that they had medical staff available to write prescriptions for their patients when required. Farrell et al. (2011) described similar practices in the UK where nurse-led and medical clinics operated concurrently.

The authority to prescribe was the main point of differentiation between some of the specialist nurse roles in this study and the role of nurse practitioners in Australia and New Zealand (Nursing and Midwifery Board of Australia, 2013; Nursing Council of New Zealand, 2017). Otherwise, the level of practice of some of the specialist nurse roles in this study was very similar to a nurse practitioner. It could be put forward then that the title 'nurse practitioner' is only distinguishable from other advanced practice roles by an authority to prescribe medication and the nurse's employment in a nurse practitioner role. Two of the interview participants in this study had completed their Master of Nursing Practice degrees however practiced as specialist nurses as no nurse practitioner roles existed in gynaecological cancers in their jurisdiction. As these nurses identified, the knowledge and experience gained through their Master's degree cannot be erased, but unless they are employed in a nurse practitioner role there is no recognition of this. The nurse practitioner role is well defined in Australia and New Zealand (Nursing and Midwifery Board of Australia, 2013; Nursing Council of New Zealand, 2017), but no framework exists to define or credential nursing roles that exist between entry level registered nurses and advanced practice nurses not working in nurse practitioner roles. Specialist nurses in this study who were involved in nurse-led clinics, or who held a Master's degree, engaged in more advanced nursing practice than those who did not. Whilst all of the specialist nurse participants in this study were 'specialists' in the field of gynaecological oncology, their *level* of practice differed.

In their framework for career and education for cancer nurses in the UK, the Royal College of Nursing (2017) distinguished specialist nursing practice from advanced practice. They reserved the term 'specialist' to refer to the clinical context within which the nursing role was executed, separating this from the nurses' level of practice on a scale from novice to expert (Royal College of Nursing, 2017). The aim of

the framework was to harmonise role titles, distinguish levels of practice, inform academic preparation, and develop cancer-specific nursing outcomes (Royal College of Nursing, 2017). Utilising the 'Skills for Health' framework (Skills for Health, 2010) the Royal College of Nursing (2017) identified four levels of registered nurse practice in specialist cancer services – registered practitioners, senior practitioners, advanced practitioners and consultant practitioners. They specify that to progress from registered practitioner level to senior practitioner level the nurse must engage in continuing professional development and postgraduate education (Royal College of Nursing, 2017). Progression to an advanced nurse practitioner role required a Master's degree and a Doctorate was required to be employed at the consultant practitioner level (Royal College of Nursing, 2017). Although competency frameworks and broad education frameworks for cancer nursing are in place in Australia and New Zealand (Aranda & Yates, 2009; New Zealand Ministry of Health, 2009, 2014), there is no professional framework or standardised nomenclature to link this to. Standardised nomenclature and a professional framework would allow for clearer definition of the differences in the level of practice between the specialist nurses in this study. Differentiation of the specialist nurse role in regard to level of practice is required, along with differentiation from other emerging roles such as that of cancer care coordinators.

Responsibility for care coordination

The responsibility for care coordination was highlighted as an important aspect of specialist nurse care by all key stakeholders in this study. However, the level of coordination provided by each specialist nurse in this study differed - some participants were the named coordinator and others worked alongside a designated cancer care coordinator. A few participants in this study coordinated the care of women and the team for only a specified period of the woman's disease trajectory and either handed this role onto another coordinator, or this role ceased to exist for the woman thereafter. In some cases, the designated

care coordinator who worked alongside the participants in this study was also a nurse, or sometimes an allied health professional. Evans (2010) emphasises the need for a multidisciplinary approach to be taken to care coordination and that multidisciplinary team members other than nurses can fill the role. However, the 'cancer nurse coordinator' or 'cancer care coordinator' roles described in the Australian and New Zealand literature greatly resemble that of the specialist nurses in this study or indeed were specialist nurse roles (Bishaw & Coyne, 2015; Cancer Nurses Society of Australia, 2008; Collinson, Foster, Stapleton, & Blakely, 2013; Durcinoska, Young, & Solomon, 2017; Freijser et al., 2015; Jackson, 2008; Monterosso & Platt, 2016; Platt et al., 2008; Walsh et al., 2011; Yates, 2004). This study has exposed the lack of differentiation between the role of a care coordinator and that of a specialist nurse. Indeed, the issue appears to be one more of role proliferation and non-standardised nomenclature rather than differentiation. A Community Affairs Senate Committee of the Australian Government recommended in 2005 that cancer coordinator roles be established for all cancers by all State and Territory governments of Australia and be modelled on the breast cancer nurse role (Australian Government, 2014). At a similar time, the New Zealand Government committed funds to the development of cancer care coordinator roles, also referring to CNS roles that already existed as examples of the care that was to be provided by the coordinators (Collinson et al., 2013). It is thus plausible that there are few differences between specialist nurse and care coordinator roles beyond role title.

It could be postulated that the coordinator role is more focused on the logistics and navigation of cancer care, and the specialist nurse a provider of expert, advanced clinical care. Yet it does not follow with the results of this study where 'coordinators' ran nurse-led clinics and 'specialist nurses' coordinated care. Services may not be large enough to require both a 'specialist' and a 'coordinator' and thus one nurse may fulfil both roles. In larger services with high patient volumes, the division of 'specialist' and

'coordination' activities may be a pragmatic alternative to a case management approach. The participants in this study strongly supported the inclusion of a specialist nurse or nurse coordinator in the multidisciplinary team to care for women with gynaecological cancers at all stages along their disease trajectory. However, standardisation of nomenclature and clear delineation of roles would improve recognition and understanding of specialist nurse and coordinator roles.

Regardless of the role title held by the nurse, there were significant threats to the stability of the model where the specialist nurse or nurse coordinator was the 'keystone' in the provision of care.

Threats to stability

Many aspects of the 'keystone' model were reflected in a study by Regan, Mills, and Ristevski (2012) who described two cancer care coordinator roles in a large regional Australian hospital. They described the cancer care coordinators as the "lynchpin" of the team and "everything to everyone" whereby both patients and team members relied heavily on the nurses Regan et al. (2012, p. 16). Regan et al. (2012) identified the potential for deskilling of patients and team members when the cancer care coordinator completed tasks that the patient or multidisciplinary team could do for themselves. Some participants in this study expressed concern that patients and the multidisciplinary team could become 'dependent' on the specialist nurse.

For some specialist nurses in this study, being the 'keystone' for both women with a gynaecological cancer and the multidisciplinary team was demanding. This study identified many pressures on the specialist

nurse which, owing to the 'keystone' role that the specialist nurse played in the structure, were threats to the stability and sustainability of this model. Increasing workloads; poor role recognition, identity and definition; a lack of support; were all cited by specialist nurses in this study as sources of stress. Additionally, a model of care where one person is the 'keystone' does not align with objectives for cancer care coordination that specified that care coordination should be the responsibility of the whole team and not solely the task of an individual (Evans, 2010).

Specialist nurses in this study worked regular unpaid overtime to fulfil their expanding roles and provide 'time' to women with gynaecological cancers. In studies of other cancer nurse specialists, heavy workloads also resulted in regular unpaid overtime, specialist nurses taking work home, the omission of important aspects of care such as holistic needs assessments, or achieving only the bare minimum of care (Cumming, 2012; Cusworth et al., 2015; Leary, Bell, Darlison, & Guerin, 2008; Leary et al., 2016; Leary, White, & Yarnell, 2014; Taylor, Stiff, & Garnham, 2014). Administrative tasks were performed by 94 per cent of specialist nurses surveyed in this study and was identified in other studies 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., 2014). Specialist nurses in this study who had access to administrative support reported that it liberated time for them attend to clinical matters. This was supported by Leary et al. (2016) who reported that overtime levels were lowest for CNSs with administrative support. Specialist nurses in this study without administrative support all believed that administrative support would reduce their workload.

The specialist nurses in this study were reluctant to take leave, anticipating that it would lead to women not receiving care and exacerbate already unmanageable workloads. Many of the specialist nurses in this study were not able to attract other nurses to cover their role or could not secure funding for leave cover, as reported in other studies of oncology clinical nurse specialists (Catt, Fallowfield, Jenkins, Langridge, & Cox, 2005; Leary et al., 2016; Leary et al., 2014; Taylor et al., 2014).

Some of the specialist nurse participants in this study expressed feeling exhausted by their jobs and reported affects congruent with burnout. Some studies have investigated burnout in oncology nurses using the Maslach Burnout Inventory, which measures for emotional exhaustion, depersonalisation and personal accomplishment (Barnard, Street, & Love, 2006; Eelen et al., 2014; McMillan et al., 2016). In all of these studies, oncology nurses experienced moderate to low levels of burnout however McMillan et al. (2016) identified that workload was a significant predictor of emotional exhaustion. Contrary to the findings of this study, Barnard et al. (2006) found that burnout was not influenced by levels of supervisor support, though peer support was positively correlated with personal accomplishment.

Poor role recognition, identity and definition all pose threats to the success and future of the specialist nurse role in gynaecological oncology. Management support was identified as a major facilitator and indicator of success of clinical nurse specialist roles (Black & Farmer, 2013; Bousfield, 1997; Kilpatrick, Tchouaket, Carter, Bryant-Lukosius, & DiCenso, 2016; Leary et al., 2014). For those nurses 'working between worlds' there was a lack of role recognition from their nursing managers. A low response rate was received from nurse managers in this study and those who did respond did not have a specialist nurse in their team, thus their perspective on this issue was not gained.

It was evident through the accounts of specialist nurse participants in this study that the medical discipline was involved in the creation and guidance of gynaecological oncology specialist nurse roles. Although all interview and focus group participants in this study formally reported to a nurse manager, many described how doctors influenced their scope of practice, particularly in regard to the assumption of responsibilities traditionally within the domain of medicine. Where most specialist nurse participants in this study believed they had the support of their medical colleagues, they speculated that their nursing managers either did not understand their role or did not support their advanced level of practice. For some, this perceived lack of support and recognition diminished their pride as a nurse and led to feelings of alienation and estrangement from the nursing discipline. Bousfield (1997) recommended that specialist nurses and nursing managers work together to set goals and make and evaluate plans relating to specialist nurse roles to foster acceptance and recognition. Kilpatrick et al. (2016) also asserted that for a role to be recognised, it must be well defined with minimum education requirements, consistent legislation and regulation across jurisdictions, and clear practice boundaries. Specialist nurses in this study desired the creation of guidelines for practice across the continuum of care to standardise practice among nurses and define scope of practice. The poor recognition, identity and definition of their roles were not only sources of stress for the specialist nurses but also threaten their future existence. Without 'role legitimacy' specialist nurse roles exist at the discretion of employing organisations who control funding of these positions (Bousfield, 1997; Brown, 1998).

In many cases in this study, specialist nurses performed their role outside of a nursing team. Most specialist nurses in this study worked autonomously within their workplaces and in silos from each other, with some reporting that they missed the informal support and camaraderie of working in a nursing team.

While the recognition of the multidisciplinary team was valued by the specialist nurses in this study, they also identified that nursing peer support was important as identified in studies by Barnard et al. (2006) and Black and Farmer (2013). A study by Honkavuo and Lindström (2014, p. 123) described this as a "nursing communion" and identified that nurses required both this kind of collaboration, along with professional supervision, to feel supported in the clinical setting. Effective clinical supervision was identified in other studies to reduce burnout in oncology and general nurses (Black & Farmer, 2013; Honkavuo & Lindström, 2014; Koivu, Saarinen, & Hyrkas, 2012; McMillan et al., 2016). Participants in this study who did not have access to clinical supervision reported work-related stress and exhaustion that impacted their personal well-being. Taylor et al. (2014) suggested that the provision of effective and independent clinical supervision be non-negotiable in advanced and specialist nursing roles. It is evident from this study that, where possible, specialist nurses feel more supported when they maintain proximity to a nursing team. Additionally, several participants in this study expressed that they would like to be part of a network of gynaecological oncology specialist nurses. Although such a group exists in Australia, some participants were not aware of it. The theme 'A siloed workforce' highlighted the isolation experienced by some of the specialist nurses in their role and the need for gynaecological oncology specialist nurses to connect with each other.

Threats to the stability of the specialist nurse as the 'keystone' of gynaecological cancer care provision included both stressors affecting specialist nurses and the lack of legitimacy of the role. Mitigation of these threats to stability, including the provision of effective professional support for specialist nurses, would strengthen the role to provide a model of care that is acceptable to all stakeholders. The specialist nurse roles that have emerged over recent years now require legitimisation through the provision of competency standards, minimum education requirements and credentialing from the nursing profession.

The process of role legitimisation would afford specialist nurses the recognition and validation that was lacking in their role and identified as source of stress.

Trailblazers

Many of the specialist nurses who participated in this study were trailblazers in the care of women with gynaecological cancers. Several participants had held their role since its inception and all had evolved and developed their role to meet the needs of the women they cared for and their organisation. The pressures and perceived lack of support experienced by some of the specialist nurses in this study resulted from their progression into new areas of nursing such as nurse-led clinics. As these were new areas of nursing there were no guidelines for them to follow. Whilst the specialist nurses did not explicitly identify themselves as trailblazers, their accounts of the effort they had put into conceiving, developing and promoting their roles were evidence that they had forged new pathways in the nursing care of women with gynaecological cancers. Several specialist nurses in this study had progressed their roles from what were likened to 'physician's assistant' roles to advanced-practice nursing roles. Yet, this study identified that the medical profession offered the most support to specialist nurses. It was evident that medical professionals recognised specialist nurses as the best healthcare professionals to meet many of the needs of women with gynaecological cancers. Many of the specialist nurse roles described in this study were developed from the ground-up, motivated by the nurses' and medical specialists' desire to improve the experiences and outcomes of women with gynaecological cancers. The ground-up development of many of these roles meant that the nursing profession did not have control or governance of the roles. The role proliferation that has occurred in this field must now be met with effort from the nursing profession to ensure that role legitimacy is achieved.

Although the specialist nurse role in gynaecological oncology has been developed by many individuals without guidance or governance, their practice is sufficiently similar to form a definition of their role.

Defining the specialist nurse role in gynaecological oncology

There was consensus among stakeholders as to the key aspects of the specialist nurse role in gynaecological oncology in Australia and New Zealand. The diverse perspectives of the specialist nurse role gained through the participation of multiple disciplines in this study, along with the systematic review of the literature, has allowed a general definition of the role to be proposed as follows:

The gynaecological oncology specialist nurse is a registered nurse, holding a post-graduate qualification, who is experienced in the care of women with gynaecological cancers. The specialist nurse provides a point of contact within the health care system for the woman with a gynaecological cancer and is involved in the provision of information and education, holistic and expert clinical care, assessment and referral, care coordination, and advocacy for the woman. The specialist nurse is integral to the multidisciplinary team as a communicator, coordinator, patient advocate and mentor. The specialist nurse is a point of contact for primary care providers and other health professionals outside of the treating organisation.

What this definition lacks are precise education and experience requirements to fulfil the role. It also does not accommodate nurses currently practising in the role who do not hold a post-graduate qualification and may thus be best used as a definition for future incumbents to the role. Likewise, the definition does not specify nomenclature for the role given that standardised nomenclature does not

exist in Australia. The majority of nurses in this study believed that the role required Master's level educational preparation. However, until graduate education levels and nomenclature become aligned and standardised across Australia, and to a much lesser extent New Zealand, it remains a difficult task to specify the 'level' or 'levels' at which the role should be practiced and hence the education preparation required. Definition of the scope of practice of specialist nurses in gynaecological oncology through guidelines for practice at key points along the disease trajectory is discussed in Chapter 8 under 'Recommendations'.

Defining the specialist nurse role is an important step in identifying how specialist nurses can meet the needs of all women with gynaecological cancers. This study has exposed populations with gynaecological cancers whose needs have not yet been explicitly identified or who may not have access to specialist nursing care.

Addressing need and disparity

This study had identified that specialist nurses are well positioned to meet many of the needs identified by women with gynaecological cancer in the integrative review in Chapter 3. It has shown that the specialist nurse role involves the provision of information and education, holistic and expert care, care coordination and a central point of contact for the woman. This sphere of activity aligns well with the informational, physical and practical needs identified in the integrative review. However, neither this study, nor any other, have determined the efficacy of specialist nurses in identifying and meeting the needs of women with gynaecological cancers. Additionally, the needs of several groups of women with gynaecological cancers remain unknown. The specific needs of Indigenous populations and women of culturally and linguistically diverse (CALD) backgrounds have not been investigated. Of similar concern is the potential disparity in provision of specialist nursing support for women treated in the private health

system and those living in regional or rural areas. Eighty-two per cent of the specialist nurses responding to the survey, and 95 per cent of the nurses participating in the interviews and focus groups worked in the public system. Nearly 30 per cent of treatment team respondents did not have a gynaecological oncology specialist nurse in their team of which half worked in the public health system and half in the private system. The level of access to specialist nursing care of women with gynaecological cancers in Australia and New Zealand has not been determined through this study, though these figures provide an insight into the disparity that exists. Future research should determine access and equity to specialist nursing care for women with gynaecological cancers and propose strategies to ameliorate service deficiencies.

Limitations

Women with gynaecological cancers, as key stakeholders in the specialist nurse role, were not included in this study as evidence relating to their experiences and needs already existed. The two bodies of evidence systematically reviewed relating to experiences of women with gynaecological cancers cared for by a specialist nurse, and the needs of women with gynaecological cancers, bring the perspectives of women with gynaecological cancers to this study. The systematic review included a study from Australia and the integrative review included several large studies from Australia and one from New Zealand. Although Maori women were included in the New Zealand study, it was not clear whether Indigenous women were included in the Australian studies. Explicit research of the needs and experiences of both Indigenous and Maori women with gynaecological cancers in Australia and New Zealand is imperative given their higher rates of incidence, and poorer survival and mortality rates compared to their non-Indigenous counterparts. The decision to include or exclude women with gynaecological cancers in this study was carefully considered by the researcher and supervision team. It was recognised that there is a need to

engage women with gynaecological cancers in research that tests the efficacy of specialist nursing care or interventions such as guidelines for practice or a model of care. However, before such experimental research could be undertaken, or guidelines or models of care developed, the gynaecological oncology specialist nurse role required definition and the perspectives of other key stakeholders in the role determined. The inclusion of women in future research relating to the development, implementation and evaluation of guidelines for practice for specialist gynaecological oncology specialist nurses and the efficacy of specialist nursing care is imperative.

The exact size of the population from which the sample for this study was taken could not be determined owing to the lack of data on nurses caring for women with gynaecological cancers in non-specialised roles. Representativeness of the sample was not sought given the qualitative design of the study, however additional statistical analysis could have been applied if this was achieved. At least 20 centres offering treatment of gynaecological cancers were identified across Australia and New Zealand and it was deemed time and resource prohibitive to apply for ethics approval from each organisation. It is acknowledged however that this would have been the most effective and representative method of recruitment. Both the recruitment from professional organisations, and the use of an online survey, may explain the low response rate from registered nurses other than specialist nurses. Nurses in 'higher' roles are more likely to be members of professional organisations and though snowballing to other colleagues was encouraged, this didn't seem to impact nurse participation. Nurses working on hospital wards providing direct patient care have limited computer access during work hours, which may account for their limited response to the survey. Direct recruitment at each of the hospitals treating women with gynaecological cancers, or the use of a paper-based survey, may have improved this response rate though again it was considered time and cost prohibitive. The use of an anonymous online survey to collect data from treatment team

members was chosen to allow better accessibility to these stakeholders. This did however prevent in-depth exploration of issues with them, and the opportunity to clarify and elaborate on topics, as an interview would have allowed. The anonymity of the online survey also prevented the direct matching of survey responses to interview and focus group participants.

Determining the levels of access to specialist nursing care for women with gynaecological cancers in Australia and New Zealand was beyond the scope of this study. However, nearly 30 per cent of treatment team participants reported that they did not have a specialist nurse in their team, indicating that access to specialist nursing care may be inequitable for women with gynaecological cancers and this warrants further investigation. Additionally, the vast majority of specialist nurse participants worked in the public system indicating that women treated in the private system may not receive access to specialist nursing care.

As there was known disparity in the role titles of specialist nurses caring for women with gynaecological cancers prior to commencement of the study, the list of role titles listed for treatment team members included that of 'Cancer Service Coordinator'. This was intended to identify managers of cancer services though possibly confused some specialist nurses who have the word 'coordinator' in their title as some of the responses to the survey under this title seemed to be from the perspective of a specialist nurse. As the survey was completely anonymous there was no way of identifying if this was the case. These responses were still analysed given that the questions asked in this section of the survey were very similar to those asked during the interview and focus groups.

Specialist nurses were not asked to provide details of their pay rates or the level of their industrial award at which they were employed. The relevance of this became apparent when some interview participants revealed that they were being paid as level 2 nurses. Although some participants did offer information on their pay, the failure to collect this information from all participants prevented determination if the difference in job titles equated to differences in pay.

No consideration of the economic value of specialist nurses was made in this study, nor were details of their case-loads collected. Specialist nurses were found to be working large amounts of unpaid overtime and it was unclear if this was due to higher case-loads or other factors. The maximum recommended caseload for a gynaecological oncologist in Australia is 100 new cases per year (Cancer Australia & The Royal Australian College of Obstetricians and Gynaecologists, 2011), however no such recommendation exists for the case-loads of specialist nurses

The identification of women's issues in this study indicate that it could have been conducted through a feminist lens which would have resulted in a different interpretation of the results. Whilst not a limitation as such, it should be recognised that the adoption of a feminist methodology would have yielded a different perspective on the data.

Chapter 8 – Conclusions and recommendations

Summary of Thesis

This Interpretive Description study was 'scaffolded' by the first three chapters of this thesis which provided the background to the project and a review of the literature. The researcher was identified as an 'insider researcher' and 'located' within the field of gynaecological oncology. The incidence, survival and mortality rates and treatment of each of the gynaecological cancers in developed nations where gynaecological cancer treatment was available, were compared with those in developing nations where treatment was mostly not available. A brief history of specialist and advanced practice nursing was provided along with an account of the emergence of specialist nurse roles in cancer and gynaecological oncology. The gynaecological cancer specialist nurse role has developed in Australia and New Zealand without clear direction or control and has never been formally defined. The main aim of this study was to describe and define the specialist nurse role in the provision of gynaecological cancer care in Australia and New Zealand.

Chapters 2 and 3 of this thesis presented papers published and under review of a systematic review and integrative review respectively. The systematic review in Chapter 2 considered the experiences of women with gynaecological cancers who received care from a specialist nurse. The three major themes resulting from the qualitative review related to the provision of tailored, accessible and expert care to women with gynecological cancer by specialist nurses. The integrative review in Chapter 3 identified the needs of women with gynaecological cancers across their disease trajectory. Women with all gynaecological cancers needed help to manage fears of recurrence and spread of disease, uncertainty about their future, and reported several common informational and practical needs across their disease trajectory. Women

with a gynaecological cancer needed holistic care and to know that their doctors were communicating to coordinate their care.

Chapter 4 described the methodology and methods of this study. This qualitative study employed an Interpretive Description methodology based on its aim to generate knowledge for nursing practice. Participants in this study were specialist nurses who cared for women with gynaecological cancers in Australia and New Zealand and other members of the gynaecological oncology workforce. Three data collection methods were engaged – an online survey, interviews and focus groups. Although unconventional for a qualitative study, the survey method was chosen to enable thorough description of the specialist nurse role and to engage busy medical specialists in the study. Data from the survey were analysed with descriptive statistics and a qualitative inductive content analysis. Interview and focus group data were subjected to a thematic analysis.

Chapters 5 and 6 presented the results of the online survey and individual and focus group interviews respectively. One hundred and two participants responded to the online survey of which 35 identified themselves as specialist nurses and 67 as members of gynaecological oncology treatment teams. Participation came from all states and territories of Australia and regions of New Zealand where gynaecological cancer services were offered. Survey participants identifying themselves as specialist nurses responded to questions aimed at determining their demographics, employment conditions and scope of practice. Survey participants identifying themselves as members of gynaecological oncology treatment teams provided a variety of perspectives on the specialist nurse role with representation from all disciplines that are typically included in a gynaecological oncology treatment team other than

pathology. Interviews and focus groups were conducted with a total of 19 individual specialist nurses who contributed to 13 interviews and two focus groups. Four major themes were derived from the data - 'Working between worlds', 'The patient's go-to person', 'When so much depends on one person' and 'A clearer pathway'.

Interpretation of the results culminated in the conceptualisation of a model of specialist nursing care in gynaecological oncology. This model presented the specialist nurse as the keystone of gynaecological cancer care in Australia and New Zealand. The key components of the model along with the threats to the model were discussed in Chapter 8. A definition of the gynaecological oncology specialist nurse role was also offered.

Conclusions

This study identified that gynaecological oncology specialist nurses are experienced nurses who play a key role in the provision of person-centred care to women with gynaecological cancers in Australia and New Zealand. The specialist nurse is a central point of contact for the woman with a gynaecological cancer, providing an expert source of information and support throughout their cancer experience. Largely, the type of care provided by specialist nurses to women with gynaecological cancers in Australia and New Zealand was very similar despite differences in the execution of the roles between organisations. The provision of information and education to women and their carers, the management of symptoms and side-effects, and the provision of psychosocial care and wound care were the most common clinical tasks performed by specialist nurses. There was strong support from most study participants for the involvement of specialist nurses at all stages along the disease trajectory of women with gynaecological

cancers. Despite this, the points on the disease trajectory at which specialist nurses provided care to women with gynaecological cancers differed within and between Australia and New Zealand, determined largely by the employing organisation. Few specialist nurses were involved in the care of women with gynaecological cancers at all points along the disease trajectory, with most specialist nurses entering and exiting the disease trajectory at given points. In some cases, healthcare settings employed more than one specialist nurse and a 'handover' between specialist nurses would occur at a given point on the disease trajectory. Other health care settings only funded a specialist nurse during a specific phase of the disease trajectory and a specialist nursing service was not available to women thereafter.

Specialist nurse scope of practice differed most prior to the women's admission to the healthcare service and during the survivorship period. Some specialist nurses were responsible for the triage of all women referred to their service and some conducted nurse-led clinics during the survivorship period. The specialist nurses involved in these activities used more advanced practice skills in comparison to other participants. There were also differences in the provision of care coordination by the specialist nurses in this study. Most specialist nurses were responsible for the coordination of women's care though some worked alongside a designated cancer care coordinator. The roles of cancer care coordinators and specialist nurses in the Australian and New Zealand context were found to be blurred and require further delineation and definition. Unlike Australia, standardised nomenclature was evident in New Zealand for specialist nurse roles however neither country formally credentials specialist nurses. Similarly, better guidelines were in place in New Zealand for the educational preparation of specialist nurses than for Australia, yet neither country had set minimum education requirements to fulfil specialist nurse roles. Consequently, the specialist nurses in this study held varying qualifications. Additionally, the position of

specialist nurse roles within individual hospital hierarchies differed, contributing further to the overall role confusion and lack of identity experienced by the specialist nurses in this study.

Members of gynaecological oncology multidisciplinary teams were highly supportive of the specialist nurse role. They identified the key aspects of the specialist nurse role as the provision of education and information to patients and families, coordination, navigation, communication, continuity of care, expertise, assessment, referral, support, and advocacy. Treatment team members perceived that the specialist nurse had more time to spend with women and perceived the provision of holistic, patient-centred care to be the domain of the specialist nurse. The number of treatment team members who did not have a gynaecological oncology specialist nurse working in their team indicated that many women with gynaecological cancers in Australia did not have access to specialist nursing care. Treatment team members without a gynaecological oncology specialist nurse in their team believed that women in their care with gynaecological cancers were deprived of the specialised care and support available to other patients such as those who had access to a specialist breast cancer nurse. However, those with a specialist nurse in their team cautioned against the development of dependence on the specialist nurse. Some treatment team members noted that poor role definition led to specialist nurses assuming too much responsibility, preventing women from self-managing their care, and multidisciplinary team members from fulfilling their roles. Others recognised the need for specialist nurses to engage in self-care, acknowledging the emotional burden of the role.

Gynaecological oncology specialist nurses experienced satisfaction through their close relationships with the women they cared for and their families. They saw themselves as the women's 'go-to person' playing

the role of key-contact for them within the system and providing an expert source of knowledge and support. Many specialist nurses reported that this more rewarding aspect of their role compensated for the more stressful and demanding aspects of their role. Several nurses in this study were trailblazers in their field and had forged new pathways in the care of women with gynaecological cancers. For some nurses, the ground-up development of their roles was supported by their medical colleagues but not their nursing managers. Many of the specialist nurse participants in this study played the role of 'keystone' of their gynaecological oncology service, supporting both the multidisciplinary team and the women in their care. This study identified several pressures on the specialist nurse which formed threats to the stability and sustainability of the 'keystone' model of care. Increasing workloads, poor role recognition and identity, poor role definition, and a lack of support, were all cited by specialist nurses in this study as sources of stress. Specialist nurses who had access to clinical supervision and the support of a nursing team reported far less work-related stress than those who did not. Ill-defined career and education pathways were cited by gynaecological oncology specialist nurses as barriers to attracting other nurses to the role in order to prepare them for succession or leave cover. Specialist nurses in this study desired clearer career and education pathways for specialist nurses and believed that standardised guidelines for practice, and better-defined roles, were the priorities for the future of the role.

Recommendations

Various recommendations for practice, policy, education and research were identified from this study. Specialist nurses were asked to identify their ambitions for the role into the future and the recommendations made incorporate these ambitions with other findings from the study.

Recommendations for practice

It is recommended that guidelines for specialist nurse practice at each stage along the continuum of care of women with gynaecological cancers be developed, implemented and evaluated. The findings indicate that while the overall remit of the specialist nurse in gynaecological cancer care is mostly understood, the minimum involvement of the specialist nurse at each point on the continuum of care needs to be prescribed to provide guidance to those new in the role and allow evaluation of care provided against a standard. These guidelines must also be both adaptable to apply to different organisational contexts, and not be so rigid as to prevent the provision of individualised care. Guidelines should be written in the context of gynaecological cancer specialisation but include levels of practice within the specialisation which refer to the minimum education and experience required to practice at each level. For example, a specialist nursing service that offered nurse-led follow up clinics would be adhering to the highest level of guidelines which would specify Masters' level preparation and a minimum of five years' experience in the speciality. The guidelines should refer to standardised nursing nomenclature for each level however, in the absence of such, the guidelines for practice should specify the equivalent levels of practice from all state, territory and regional enterprise agreements.

Specialist nurses in this study who had the support of their nursing managers, the multidisciplinary team and their organisation reported investing considerable time in the promotion of their role to foster recognition and 'buy-in' within and beyond teams. A common complaint of the specialist nurses in this study was that their role was not well understood in the organisation or by other health professionals. Nurses who had gained this recognition did so by giving in-service education to disciplinary groups, including nursing, and ensuring that gynaecological oncology was represented at organisational meetings. It is recommended that specialist nurses implement strategies to promote and educate others about their

role within their organisation. Additionally, nursing managers of organisations employing gynaecological oncology specialist nurses need to play an active role in the supervision and support of specialist nurse roles. Leadership of gynaecological oncology specialist nurse roles has largely rested with the specialist nurses, with the support of medicine. However, if the role is to remain sustainable into the future it requires the support and active involvement of nursing management. Nurse managers must be actively involved in specialist and advanced nursing roles and play a role in determining their scope of practice.

Organisations must make available independent clinical supervision to all gynaecological oncology specialist nurses. A significant difference in the level of work-related stress was reported between specialist nurses in this study who had access to clinical supervision and those who did not. The reliance of both patients and the multidisciplinary team on the specialist nurse requires that the specialist nurse has access to effective professional support. Specialist nurse roles should be actively supervised by nursing managers and, ideally, closely located to nursing teams where informal peer support is available. The involvement of specialist nurses in national and international interest groups is also recommended to foster collegiate relationships and address the isolation experienced by some nurses in their role.

Recommendations for policy

Definition and recognition of specialist nurse roles is arduous in a system without standardised nomenclature and pay scales. A standardised career structure for nurses in which specialist nursing roles occupied designated levels would enable clear definition and delineation of roles and in turn allow minimum education and experience requirements to be applied for these roles. Such standardisation would require significant collaboration between professional and industrial nursing bodies within each

country. There is a clear need for registration or credentialing of nursing roles that lie between standard nursing registration and nurse practitioners.

In the absence of a national structure within which the role can be located, it is recommended that work be done at a professional organisation level such as the Cancer Nurses Society of Australia to determine levels of practice within the role, and link these to industrial awards within each state, territory, district and region. With the endorsement of a professional body, and guidelines for different levels of practice, the specialist nurse and employing organisation would be able to match the needs of the organisation to a standardised level of specialist nursing care. This would facilitate parity across organisations, allow clearer education and career pathways to develop, and enable better succession planning.

Local policy within healthcare organisations must cover all aspects of specialist nursing practice, particularly the operation of nurse-led clinics. Permission and support from a medical specialist does not provide legal protection for the specialist nurse should an adverse event occur in a nurse-led clinic. Healthcare organisations must have policies in place guiding the scope of practice of nurses operating nurse-led clinics.

Recommendations for education

At present, gynaecological oncology specialist nurses must prepare themselves educationally by gathering the skills and knowledge they identify as necessary to complete their role from a variety of sources. Nearly all specialist nurse participants desired a post-graduate level formal award qualification that would

specifically prepare them to be a specialist gynaecological oncology nurse. However, they acknowledged that this was not likely to be available in the near future in Australia or New Zealand due to the relatively small numbers of women with gynaecological cancers in each country and the subsequent demand for the role.

Setting levels of practice within the specialisation would allow appropriate minimum education requirements to be set for each level which would inform the development of educational pathways. It is recommended that a post-graduate elective unit in gynaecological oncology nursing be developed that can be taken as part of a relevant post-graduate qualification such as in women's health or oncology nursing. An online mode may be the most accessible and cost-effective way of delivering such a unit.

Recommendations for research

The development, implementation and evaluation of two sets of guidelines for practice are recommended. As suggested above, guidelines for specialist nursing practice at key stages along the continuum of care should be developed. In addition, specific guidelines for the operation of nurse-led clinics should also be developed. Both projects would be well suited to a Delphi design whereby key stakeholders - specialist nurses, medical specialists, nursing managers, legal counsel, nursing professional bodies and women with gynaecological cancers - are engaged to determine scope of practice. As it is evident that disparity in access to specialist nursing care exists, populations without access to this care should be identified and prioritised in the implementation of new guidelines.

Further research into the needs of women from vulnerable populations with gynaecological cancers, including those from Indigenous and CALD backgrounds, is recommended to allow specialist nurses to provide appropriate care to these women. The level of access to specialist nursing care of women from

vulnerable populations with gynaecological cancers should be determined and their experiences of specialist nursing care sought.

Economic and needs-based evaluation of holistic nurse-led clinics compared with standard medical follow-up should be completed. Specialist nurses have extended their scope of practice to ease the burden on medical staff, but the outcomes of this should be closely monitored.

Summary

Specialist nurses are playing a significant role in the provision of gynaecological cancer care in Australia and New Zealand. Many specialist nurses have been trailblazers in their field, developing their roles to address the needs of women with gynaecological cancers. These roles however to do not clearly fit within existing nursing career structures. Whilst somewhat standardised in New Zealand, nursing nomenclature is disparate between the states and territories of Australia which has led to significant variation in the role titles, scope of practice, and education and experience levels of specialist nurses as identified in this study. The standardisation of nomenclature relating to specialist nurse roles at a national level would allow minimum education and experience requirements to be set for specialist nursing practice. In turn, this would allow for the identification of clear career and education pathways that are currently lacking for gynaecological oncology specialist nurses. With formal recognition at a national level, greater acceptance and support for specialist nursing roles at an organisational level, and from the nursing profession, could be expected.

The development, and widespread adoption, of guidelines for practice across the disease trajectory would address variance in specialist nurse practice between organisations and ensure consistency and equity in

the care provided to women with gynaecological cancers. Evidence-based guidelines for practice should also direct the care of Indigenous women and women from CALD backgrounds with gynaecological cancers whose needs are yet to be identified through research. Where specialist nurse practice is advanced, guidelines for practice will provide the legal protection for specialist nurse practice that is currently largely directed by medicine. Further research is required to determine the value and safety of advanced specialist nursing roles in gynaecological oncology. With formal structures and greater standardisation of practice, the profile and identity of gynaecological oncology specialist nurse roles can be raised. In turn, this can allow promotion of the role to other healthcare professionals and women with gynaecological cancers. Widespread acceptance of the role will lead to the implementation of more gynaecological oncology specialist nurse roles and increase access to specialist nursing care for women with gynaecological cancers.

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Appendices

Appendix I MUHREC Ethics approval

MONASH University
Monash University Human Research Ethics Committee (MUHREC)
Research Office

Human Ethics Certificate of Approval

This is to certify that the project below was considered by the Monash University Human Research Ethics Committee. The Committee was satisfied that the proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research* and has granted approval.

Project Number:	CF15/4692 - 2015002023	
Project Title:	Understanding how specialist nurses contribute to the care of women with gynaecological cancer in Australia - a mixed-methods study	
Chief Investigator:	Assoc Prof Meredith McIntyre	
Approved:	**From:** 8 January 2016	**To:** 8 January 2021

Terms of approval - Failure to comply with the terms below is in breach of your approval and the Australian Code for the Responsible Conduct of Research.

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, before any data collection can occur at the specified organisation.
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must include your project number.
6. **Amendments to the approved project (including changes in personnel):** Require the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

[redacted]

Professor Nip Thomson
Chair, MUHREC

cc: Ms Olivia Cook, Dr Susan Lee, Ms Katrina Recoche

Monash University, Room 111, Chancellery Building E
[redacted]

Appendix II Participant Invitation

Invitation to participate

Research project: How do specialist nurses contribute to the care of women with gynaecological cancer?

Dear (ANZGOG / CNSA) Member,

My name is Olivia Cook and I am conducting a research project as part of my PhD studies at the School of Nursing and Midwifery at Monash University under the supervision of Associate Professor Meredith McIntyre, Dr Susan Lee and Ms Katrina Recoche.

This research is aimed at understanding how specialist nurses contribute to the care of women with gynaecological cancer in Australia and New Zealand and we are seeking both specialist nurses and all other members of the gynaecological oncology treatment team to participate. Further details of the aims of the project and what it entails are provided in the explanatory statement/s attached. It is essential that you read the explanatory statement/s before agreeing to participate in this research.

I invite **all members of the gynaecological oncology workforce (including specialist nurses)** to participate in this research by completing the electronic survey. The survey can be taken by clicking on this link and your responses are completely anonymous:
https://monashmnhs.qualtrics.com/SE/?SID=SV_6YbO8bg6V6B4bHv

I invite **specialist nurses** to participate further by being interviewed, either face to face or via telephone or videoconference, and/or contributing to a focus group discussion. Focus group discussions will be held at the ANZGOG and CNSA 2016 annual conferences to be held in April in Sydney and May in Cairns respectively.

To register your interest to participate in a focus group, please click this link: http://goo.gl/forms/G5z5FOSJMz

To register your interest to participate in an interview, please click on this link: http://goo.gl/forms/WAkLIxYyAS

This project has been approved by Monash University Human Ethics Committee (MUHREC) CF15/4692 - 2015002023. Should you require any further information, please contact me via email [redacted] or telephone +61 417 372 332. Your involvement in this project is greatly valued.

Yours sincerely,

Olivia Cook

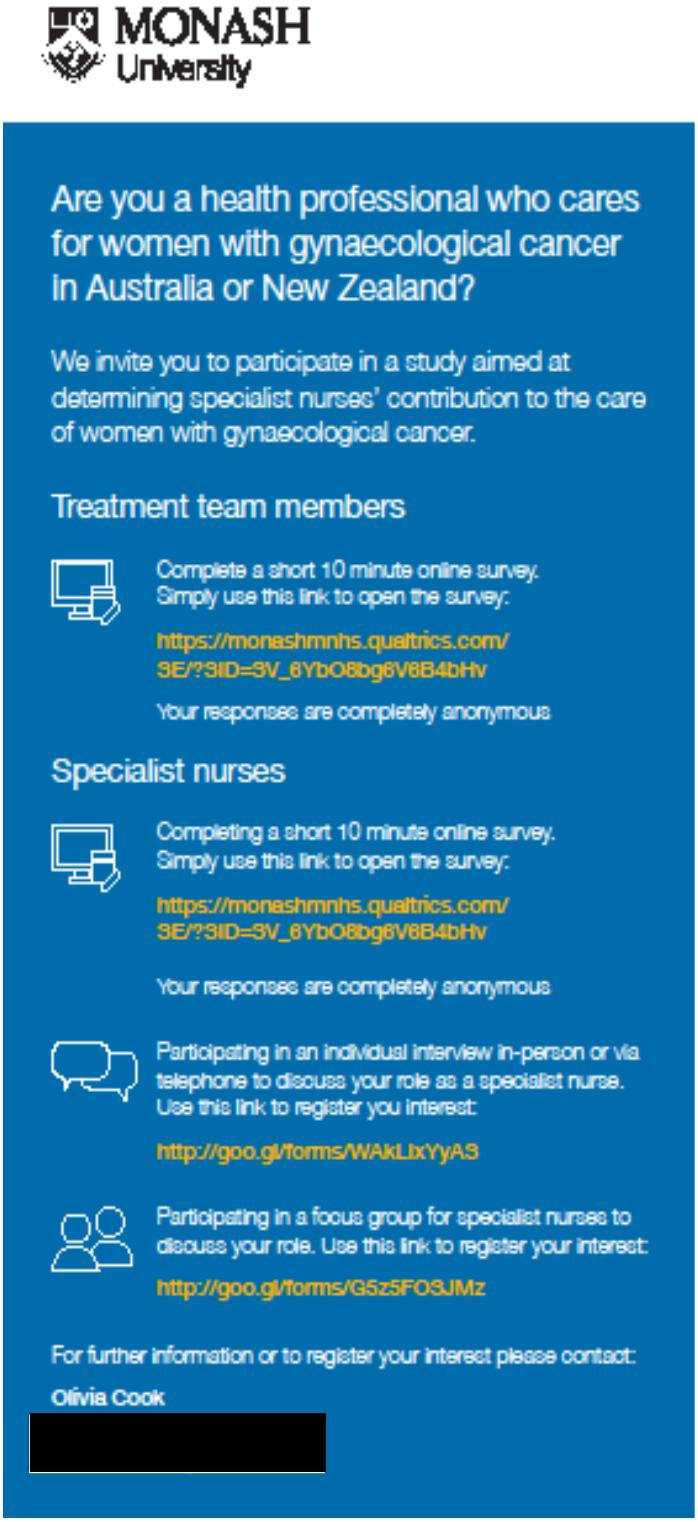
PhD Candidate

School of Nursing and Midwifery

Faculty of Medicine, Nursing and Health Sciences

Monash University, Peninsula Campus

Appendix III Brochure advertising study



Appendix IV Interview and focus group explanatory statement

MONASH University

EXPLANATORY STATEMENT - Interviews and Focus Groups

Project Title: Understanding how specialist nurses contribute to the care of women with gynaecological cancer in Australia and New Zealand.

Project Number: CF15/4692 - 2015002023

Chief Investigator: Associate Professor Meredith McIntyre
Faculty of Medicine, Nursing and Health Sciences
[redacted]

Student's name: Olivia Cook
[redacted]

My name is Olivia Cook and I am conducting a research project as part of my Doctor of Philosophy studies at the School of Nursing and Midwifery, Monash University. You are invited to take part in this study and are encouraged read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone numbers or email addresses listed above.

What is the purpose of the research?

The overall aim of this study is to determine how specialist nurses in Australia and New Zealand contribute to the care of women with gynaecological cancer and what the role means within the context of gynaecological cancer care within Australia now and into the future. The focus groups and interviews specifically aim to:

1. Understand how specialist nurses perceive their role within the context of gynaecological cancer care in Australia and New Zealand and identify the challenges they face in executing their role.
2. Determine how specialist nurses see their role in the future and identify opportunities and barriers for development of the role
3. Make recommendations for a model of specialist nursing care for women with gynaecological cancer.

What does the research involve?

This arm of the study involves both focus group and individual interviews. The focus groups will be held at the 2016 annual conferences of the Australia and New Zealand Gynaecological Oncology Group (ANZGOG) and Cancer Nurses Society of Australia (CNSA) in Sydney and Cairns respectively. The interviews will either be conducted in person at the CNSA conference or via telephone or video

conference link as per the participant's preference. The focus groups and interviews will be audio recorded.

Why were you chosen for this research?
This arm of the study is seeking participants who identify themselves as a specialist nurses who care for women with gynaecological cancer.

Source of funding
This research is part of a Doctor of Philosophy study for which the student has received an Australian Postgraduate Award. The student and their supervisors have no conflicts of interest to declare.

Consenting to participate in the project and withdrawing from the research

1. A signed consent form is required for participation in the focus groups and/or individual interviews. This will be provided when you register your interest in being involved in the research either in hard copy or via email at the preference of the participant. Signed consent forms may be returned to the researcher via email, the pre-paid self-addressed envelope provided or directly to the researcher at the focus group or individual interview.
2. Even if you have signed a consent form, you have the right to withdraw your participation in a focus group or interview at any stage. You may withdraw your responses up to one month after you have been provided with a copy of the transcript for validation.

Possible benefits to participants

This study will be the first to investigate how specialist nurses around Australia and New Zealand are contributing to the care of women with gynaecological cancer. The focus groups and interviews will give you the opportunity to contribute your experiences and opinions to discussions about the role and its future. Along with the results of a survey also being conducted as part of this research, your responses will be utilised to make recommendations for the future of the role and possible development of a model of care.

Inconvenience / risk to participants

The focus groups will run for no longer than 2 hours and the individual interviews no longer than 1 hour. Focus group and interview participants may feel tired after their contribution, particularly when scheduled among other conference activities. As you will be asked to identify challenges in your work this may conjure some emotion for you.

Payment
No payment or reward, financial or otherwise, is offered for participation in this research.

Confidentiality
Data collected through the focus groups and interviews will be de-identified through the use of pseudonyms. You will not be identified in any papers, reports or thesis arising from this research. Focus group participants will be required to sign a confidentiality agreement ensuring that they do not disclose the contributions of other participants outside of the focus group.

Storage of data

Data generated through the interviews and focus groups (recordings, field notes and transcripts) will be stored in a locked cabinet in the PhD office of Monash University's Peninsula Campus. Electronic data will be stored on a password protected faculty computer. The data, electronic and hard copy, will be destroyed according to Monash University's Retention and Disposal Authority guidelines after 5 years unless deemed at that point to be useful for future research.

Use of data for other purposes

De-identified data and analysed findings may be made available to other researchers seeking permission from the chief investigator after completion of the current study, though this is not foreseeable.

Results

The findings of this research will be reported in a thesis and may be presented at conferences and published as journal articles. The publication of the results of the focus groups and interveiws is expected in early 2018 and a summary of the key findings may be made available to you by contacting the Chief Investigator.

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics (MUHREC):

Executive Officer
Monash University Human Research Ethics Committee (MUHREC)
[redacted]
Research Office
Monash University VIC 3800

[redacted]

Thank you,

Associate Professor Meredith McIntyre

Appendix V Interview and focus group consent form

MONASH University

CONSENT FORM

Interview and Focus Group Participants

Project: Understanding how specialist nurses contribute to the care of women with gynaecological cancer in Australia and New Zealand.

Project Number: CF15/4692 - 2015002023

Chief Investigator: Associate Professor Meredith McIntyre
Faculty of Medicine, Nursing and Health Sciences
[redacted]

Student's name: Olivia Cook
[redacted]

I have been asked to take part in the Monash University research project specified above. I have read and understood the Explanatory Statement and I hereby consent to participate in this project.

I consent to the following:	Yes	No
Taking part in an interview	☐	☐
Audio and/or visual recording of the interview (unless I otherwise inform the researcher prior to the interview)	☐	☐
Taking part in a focus group of up to 12 participants	☐	☐
Audio and/or visual recording of the focus group	☐	☐
The data that I provide during the interview/focus group may be used by other researchers in future projects with the permission of the Chief Investigator	☐	☐

Name of Participant _____

Participant Signature _____ Date _____

Appendix VI Survey explanatory statement

MONASH University

EXPLANATORY STATEMENT

Survey Group

Project Title: Understanding how specialist nurses contribute to the care of women with gynaecological cancer in Australia and New Zealand.

Project Number: CF15/4692 - 2015002023

Chief Investigator: Associate Professor Meredith McIntyre
Faculty of Medicine, Nursing and Health Sciences
[redacted]

Student's name: Olivia Cook
[redacted]

My name is Olivia Cook and I am conducting a research project as part of my Doctor of Philosophy studies at the School of Nursing and Midwifery, Monash University. You are invited to take part in this study and are encouraged read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone numbers or email addresses listed above.

What is the purpose of the research?
The overall aim of this study is to determine how specialist nurses in Australia and New Zealand contribute to the care of women with gynaecological cancer and what the role means within the context of gynaecological cancer care within Australia and New Zealand now and into the future. This survey specifically aims to:

1. Describe the current scope of practice of specialist nurses in their care of women with gynaecological cancer in Australia and New Zealand - identifying the what, when and how of what they do.
2. Determine how other members of the treatment team experience and perceive the role of the specialist nurse.

What does the research involve?
This arm of the study is an electronic survey that will take you between 10-15 minutes to complete. The survey can be taken on most hand held electronic devices or on a personal computer or may be offered to you as a short, structured interview.

Why were you chosen for this research?
You have been identified as someone who may be interested in the role of specialist nurses in the care of women with gynaecological cancer. To complete this survey you must either identify yourself as a

specialist nurse who cares for women with gynaecological cancer or be a member of the treatment team caring for these women.

Source of funding

This research is part of a Doctor of Philosophy study for which the student has received an Australian Postgraduate Award. The student and their supervisors have no conflicts of interest to declare.

Consenting to participate in the project and withdrawing from the research

3. As completion of the survey is entirely optional, consent is implied when you commence the survey. Verbal consent will be obtained and recorded for those wishing to take the survey as a short, structured interview.
4. You have the right to end your participation at any point without any implications. You may be sent a reminder email to complete your survey but this email will contain a link for you to request that you no longer be contacted regarding this research again.
5. Completion of the survey electronically is anonymous and as a result data cannot be withdrawn once submitted as there is no way that the researcher can trace your responses back to you. If you complete the survey as a short interview you will have the opportunity to withdraw your responses up until the point they are entered into Qualtrics. You would need to contact the researchers in order to do this.

Possible benefits to participants

This study will be the first to capture how individual specialist nurses around Australia and New Zealand are contributing to the care of women with gynaecological cancer and allow these nurses to benchmark their care against their peers. Understanding the scope of practice of specialist nurses in gynaecological oncology, along with the perceptions and experiences of key stakeholders in the role will allow recommendations to be made for the standardisation of the role through a model of care.

Inconvenience / risk to participants

This study is not collecting data of a sensitive nature and it is not anticipated that this research will cause discomfort to the participants. We understand that the participants in this research are busy people and this survey will require a commitment of 10-15 minutes of their time.

Payment

No payment or reward, financial or otherwise is offered for participation in this research.

Confidentiality

Data collected through this survey is completely anonymous – the survey itself does not require you to provide any identifying information and responses are anonymously and securely recorded in the survey platform Qualtrics.

Storage of data

Data generated through this survey (survey responses) will be owned and controlled by the Faculty of Medicine, Nursing and Health Sciences Monash University and stored in the highly secure Qualtrics Australia/Pacific region data centre. This data can only be accessed with a user name and password held by the student researcher. The data will be destroyed according to Monash University's Retention and Disposal Authority guidelines after 5 years unless deemed at that point to be useful for future research.

Use of data for other purposes

De-identified data and analysed findings may be made available to other researchers seeking permission from the chief investigator after completion of the current study, though this is not foreseeable.

Results
The findings of this research will be reported in a thesis and may be presented at conferences and published as journal articles. The publication of the results of this survey is expected in early 2018 and a summary of the key findings may be made available to you by contacting the Chief Investigator.
Complaints
Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics (MUHREC):

Executive Officer
Monash University Human Research Ethics Committee (MUHREC)
[redacted]
Research Office
Monash University VIC 3800

[redacted]

Thank you,

Associate Professor Meredith McIntyre

Appendix VII Survey transcript

Specialist nurse care in gynaecological oncology

This survey is part of a study aimed at understanding how specialist nurses in Australia and New Zealand contribute to the care of women with gynaecological cancer. This survey has two main streams. For participants identifying themselves as a specialist nurse, the survey aims to capture the current scope of practice of specialist nurses in their care of women with gynaecological cancer in Australia and New Zealand - identifying the what, when and how of their role. For those participants identifying themselves as other members of the treatment team, the survey aims to gain their perceptions and experience of the specialist nurse role within their team. We thank you in advance for your time and effort in completing this survey.

Do you work in the field of gynaecological oncology or care for women with gynaecological cancer?

- ❍ Yes (1)
- ❍ No (2)

If No Is Selected, Then Skip To End of Survey

In which country do you work?

- ❍ Australia (1)
- ❍ New Zealand (2)
- ❍ Other, please specify (3) _____

If New Zealand Is Selected, Then Skip To Which best describes your role in the...If Australia Is Selected, Then Skip To Which best describes your role in the...If Other, please specify Is Selected, Then Skip To We thank you kindly for your interest...

Answer If In which country do you work? New Zealand Is Selected Or In which country do you work? Other, please specify Is Selected

We thank you kindly for your interest in this study. The current study is aimed at determining the contribution of specialist nurses to the care of women with gynaecological cancer in Australia and New Zealand only. At this point the study does not include health professionals from countries other than Australia and New Zealand however should you wish to discuss this further, the researchers welcome your feedback. Please contact Olivia Cook on +61 417 372 332 or email Olivia.Cook@monash.edu

If We thank you kindly for you... Is Displayed, Then Skip To End of Survey

Which best describes your role in the field of gynaecological oncology?

- ❍ Specialist nurse eg CNS, CNC (1)
- ❍ Nurse Practitioner (2)
- ❍ Cancer Nurse/Service Coordinator (16)
- ❍ Nurse Manager (30)
- ❍ Nurse Educator (31)
- ❍ Registered Nurse (3)
- ❍ Gynaecological oncologist (45)
- ❍ Gynaecologist (46)
- ❍ Medical oncologist (5)
- ❍ Radiation oncologist (6)
- ❍ Pathologist (7)
- ❍ Physiotherapist (8)
- ❍ Social Worker (9)
- ❍ Dietician (10)
- ❍ Occupational Therapist (11)
- ❍ Psychologist (12)
- ❍ Researcher (13)
- ❍ Other, please specify: (15) _____

Answer If Which best describes your role in the field of gynaecological oncology? Registered Nurse Is Selected

Which best describes your registered nurse role:

- ❍ Ward nurse (1)
- ❍ Chemotherapy nurse (2)
- ❍ Radiotherapy nurse (3)
- ❍ Other, please specify: (4) _____

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

What is your exact role title?

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

Is your role exclusively gynaecological oncology related?

- ❍ Yes (1)
- ❍ No (2)

Answer If Is your role exclusively gynaecological oncology related? No Is Selected

If no, please specify other conditions that your role relates to:

- ❑ Non-malignant gynaecological conditions (1)
- ❑ Other cancer types, please specify (2) _____
- ❑ Pre or post natal care (3)
- ❑ Other (4) _____

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

Do you care for women with all types of gynaecological cancer?

- ❍ Yes (1)
- ❍ No (2)

Answer If Do you care for women with all types of gynaecological cancer? No Is Selected

If no, please specify which gynaecological cancer types you are involved with:

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

How long, in years, have you worked in this role?

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

In what year was your role created?

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

What is the role title of the person you report to in your organisation?

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

How long have you worked in gynaecological oncology?

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

How many years have you worked as a registered nurse?

Answer If In which country do you work? Australia Is Selected

In which state or territory of Australia do you work?

- ❍ New South Wales (1)
- ❍ Tasmania (2)
- ❍ Victoria (3)
- ❍ South Australia (4)
- ❍ Queensland (5)
- ❍ Western Australia (6)
- ❍ Australian Capital Territory (7)
- ❍ Northern Territory (8)

Answer If In which country do you work? New Zealand Is Selected

In which region of New Zealand do you work?

Which best describes the geographical location of your workplace? You may select more than one option if your role requires you to travel (please note that this is where you work, not where your patients come from)

- ❑ Metropolitan (1)
- ❑ Regional (2)
- ❑ Rural (3)
- ❑ Remote (4)

In which sector/s of the health care system do you work? Please select all relevant options

- ❑ Public (1)
- ❑ Private (2)
- ❑ Private, not-for-profit (3)
- ❑ Other, please specify (4) _____

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

Which of the organisation types below best describes your employer in your role as a specialist nurse?

- ❍ Public Hospital (1)
- ❍ Other public health service (2)
- ❍ Private Hospital (3)
- ❍ Private not-for-profit hospital (4)
- ❍ Private practice (5)
- ❍ Charity / not-for-profit organisation (6)
- ❍ Other, please specify (7) _____

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

What type of setting/s do you work in? You may select more than one answer.

- ❑ Surgical ward (1)
- ❑ Oncology ward (2)
- ❑ Outpatient clinic (3)
- ❑ Palliative care unit (4)
- ❑ Day oncology unit (5)
- ❑ Radiation oncology unit (6)
- ❑ Other, please specify (7) _____

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

How many hours per week are you employed in this role?

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

Do you job share this role?

- ❍ Yes (1)
- ❍ No (2)

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

Do you regularly work overtime in this role?

- ❍ Yes (1)
- ❍ No (2)

Answer If Do you regularly work overtime in this role? Yes Is Selected

If yes, approximately how many hours overtime do you work per week?

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

Please select all relevant qualifications you hold:

- ❑ Bachelors' degree (1)
- ❑ Honours degree (2)
- ❑ Graduate Certificate (3)
- ❑ Graduate Diploma (4)
- ❑ Masters degree (5)
- ❑ Doctor of Philosophy (6)
- ❑ Registered Nurse (7)
- ❑ Certificate III (8)
- ❑ Certificate IV (9)
- ❑ Other (10) _____

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

Have you completed specific education / accreditation courses to allow you to provide care in the

following areas? (please check all appropriate boxes):

- ❑ Pap Smear (1)
- ❑ Colposcopy (2)
- ❑ Chemotherapy administration (3)
- ❑ Psychosexual care (4)
- ❑ Counselling (5)
- ❑ Lymphoedema care (6)
- ❑ Palliative care (7)
- ❑ Other, please specify (8) _____

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

At which points on the disease trajectory do you provide care for women with gynaecological cancer?

Please select all relevant options.

- ❑ Pre-diagnosis / pre-admission (1)
- ❑ On admission to acute care setting (2)
- ❑ Diagnosis (3)
- ❑ Surgical treatment (4)
- ❑ Chemotherapy treatment (5)
- ❑ Radiotherapy treatment (6)
- ❑ Medical admissions post treatment (7)
- ❑ Treatment of recurrence (8)
- ❑ Survivorship (9)
- ❑ Palliative care (10)
- ❑ Other, please specify: (11) _____

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

How are women referred to your specialist nursing service? Please select all relevant options.

- ❑ Screening of patient lists (1)
- ❑ Referral from ward/unit staff (2)
- ❑ Referral from medical staff (3)
- ❑ Internal advertisement (4)
- ❑ External advertisement (5)
- ❑ Other, please specify (6) _____

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

Does your service extend to women who are not currently patients of the organisation that you work for?

- ❍ Yes (1)
- ❍ No (2)

Answer If Does your service extend to women who are not currently patients of the organisation that you work for? Yes Is Selected

If yes, how is this facilitated and funded?

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

Which of the following tasks involving direct contact with patients do you complete on a regular basis?

Please select all relevant options.

- ❑ Pre-admission assessment (1)
- ❑ Admission of patients (2)
- ❑ Psychosocial screening/assessment (3)
- ❑ Patient / family education (4)
- ❑ Counselling (5)
- ❑ Family meetings (6)
- ❑ Support group facilitation (7)
- ❑ Doctors rounds (8)
- ❑ Symptom management (9)
- ❑ Wound care (10)
- ❑ Access device management (11)

- ❑ Chemotherapy administration (12)
- ❑ Medication / analgesia administration (13)
- ❑ Discharge of patients (14)
- ❑ General patient care (15)
- ❑ Other, please specify (16) _____

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

Which of the following tasks, that do not involve direct contact with the patient, do you perform

regularly? Please select all relevant options.

- ❑ Education of staff (1)
- ❑ Patient administration eg making appointments, bookings, referrals (2)
- ❑ Treatment team meetings (3)
- ❑ Policy or procedure development/review (4)
- ❑ Professional development (5)
- ❑ Research (6)
- ❑ Other, please specify (7) _____

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

By which means do you have contact with patients? Please select all relevant options.

- ❑ In person whilst inpatient (1)
- ❑ In person as an outpatient (2)
- ❑ In person by appointment (3)
- ❑ Telephone (4)
- ❑ Skype/Google hangout/other (5)
- ❑ Support Group (6)

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

If you see women as outpatients, please select the options below that best describe the consultations:

- ❑ Outpatient consultation is conducted by medical specialist and specialist nurse together (1)
- ❑ Outpatient consultations with medical specialist and specialist nurse are conducted separately but scheduled closely on the same day (2)
- ❑ Outpatient consultations with the specialist nurse are conducted independent of follow up with the medical specialist according to a procedure or model of care (3)
- ❑ Outpatient consultations with the specialist nurse are conducted independent of follow up with the medical specialist according to the needs of the patient. (4)
- ❑ Outpatient consultations with the specialist nurse are conducted as an alternative to follow-up with the medical specialist ie a nurse-led follow-up clinic. (5)

Answer If By which means do you have contact with patients? Please select all relevant options. In person as an outpatient Is Selected

Which of the following tasks would you regularly complete at an outpatient consultation? Please select all relevant.

- ❑ Psychosocial assessment eg Distress Thermometer or QOL tool (1)
- ❑ Physical assessment eg vital signs, wound assessment (2)
- ❑ Ordering blood tests (3)
- ❑ Ordering other investigations eg ultrasound, x-ray. (4)
- ❑ Interpreting and reporting blood test results (5)
- ❑ Symptom management (6)
- ❑ Referral to other services (7)
- ❑ Coordination of treatment (8)
- ❑ Other, please specify (9) _____

Answer If If you see women as outpatients, please select the options below that best describe the consultat... Outpatient consultations with the specialist nurse are conducted as an alternative to follow-up with the medical specialist ie a nurse-led follow-up clinic. Is Selected

If you operate a nurse-led clinic, please identify the cancer type and stage of women attending the clinic and provide a basic outline of your protocol for follow-up:

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Selected

Are there any other aspects of your role that you feel have not been captured by this survey that you would like to share? If so please specify below.

Answer If Which best describes your role in the field of gynaecological oncology? Specialist nurse eg CNS, CNC Is Not Selected

Within your treatment team, is a specialist nurse employed to care for women with gynaecological cancer? This nurse's role title may be Clinical Nurse Specialist, Cancer Nurse Specialist, Cancer Nurse Consultant or similar.

- ❍ Yes (1)
- ❍ No (2)

Answer If Within your treatment team, is a specialist nurse employed to care for women with gynaecological cancer? This nurse's role title may be Clinical Nurse Specialist, Cancer Nurse specialist, Canc... Yes Is Selected

How often would you have contact with the specialist nurse?

- ❍ Daily (1)
- ❍ Weekly (2)
- ❍ Fortnightly (3)
- ❍ Monthly (4)
- ❍ Other (5) _____

Answer If Within your treatment team, is a specialist nurse employed to care for women with gynaecological... No Is Selected

If no, can you state why you do not have a specialist nurse as part of your treatment team?

Answer If Within your treatment team, is a specialist nurse employed to care for women with gynaecological... No Is Selected

Do you believe that a specialist nurse would make a valuable contribution to patient care and, if so, how?

Answer If Within your treatment team, is a specialist nurse employed to care for women with gynaecological... Yes Is Selected

What do you believe are the key aspects of the specialist nurse role?

Answer If Within your treatment team, is a specialist nurse employed to care for women with gynaecological... Yes Is Selected

How important do you think it is for the specialist nurse to be involved in patient care at given stages on the disease trajectory?

	Not at all Important (1)	Very Unimportant (2)	Somewhat Unimportant (3)	Neither Important nor Unimportant (4)	Somewhat Important (5)	Very Important (6)	Extremely Important (7)
Pre-admission (1)	❍	❍	❍	❍	❍	❍	❍
Diagnosis (2)	❍	❍	❍	❍	❍	❍	❍
Surgical Treatment (3)	❍	❍	❍	❍	❍	❍	❍
Radiotherapy treatment (4)	❍	❍	❍	❍	❍	❍	❍
Chemotherapy treatment (5)	❍	❍	❍	❍	❍	❍	❍
Post-treatment (6)	❍	❍	❍	❍	❍	❍	❍

Survivorship (7)	❍	❍	❍	❍	❍	❍	❍
Disease recurrence (8)	❍	❍	❍	❍	❍	❍	❍
Palliative care (9)	❍	❍	❍	❍	❍	❍	❍

Answer If Within your treatment team, is a specialist nurse employed to care for women with gynaecological... Yes Is Selected

Have you ever experienced role overlap with the specialist nurse and, if so, how have you handled this?

Answer If Within your treatment team, is a specialist nurse employed to care for women with gynaecological... Yes Is Selected

What do you think are the benefits and/or disadvantages to women with gynaecological cancer of care from a specialist nurse?

Answer If Within your treatment team, is a specialist nurse employed to care for women with gynaecological... Yes Is Selected

What do you think are the benefits and/or disadvantages to patients' families of care from a specialist nurse?

Answer If Within your treatment team, is a specialist nurse employed to care for women with gynaecological... Yes Is Selected

What do you think are the benefits and/or disadvantages to the treatment team of the involvement of a specialist nurse in the care of women with gynaecological cancer?

Answer If Within your treatment team, is a specialist nurse employed to care for women with gynaecological... Yes Is Selected

Are there any aspects of the specialist nurse role that have not been captured by this survey that you would like to comment on? If yes, please do so below:

Appendix IIX Focus group schedule

Focus group schedule

The overall aim of this study is to determine how specialist nurses in Australia and New Zealand contribute to the care of women with gynaecological cancer and what the role means within the context of gynaecological cancer care within Australia and New Zealand now and into the future. Specifically, this study aims to:

4. Describe what specialist nurses do in their role of caring for women with gynaecological cancer in Australia and New Zealand
5. Determine how specialist nurses and other members of the gynaecological oncology treatment team experience and perceive the specialist nurse role.
6. Make recommendations for a model of specialist nursing care for women with gynaecological cancer.

The focus groups are aimed at capturing the experiences and perceptions of specialist nurses in regard to their role of caring for women with gynaecological cancer.

Interview Schedule

1. Welcome

Good afternoon, I'd like to welcome you all to this focus group on the role of specialist nurses in gynaecological oncology. Thank you for taking the time to share your experiences and expertise today. My name is Olivia Cook and I will be conducting this focus group assisted by……. I am a PhD

candidate from Monash University Peninsula Campus and …….. is a …….. from …… ……will be taking some notes and recording some observations. Please feel free to have a glass of water or get up if you need to. You are not obligated to stay in any way and if you wish to withdraw your participation you are free to do so at any time.

2. Overview of topic

This is one of a few focus groups that I will be running aimed at understanding how specialist nurses contribute to the care of women with gynaecological cancer. These focus groups will complement a survey that you may have already completed (and if you have not already done so I encourage you to complete) considering what specialist nurses do to care for women with gynaecological cancer. You have been invited to participate in this focus group because you have identified yourself as a specialist nurse working in the field of gynaecological oncology.
The aim of these focus groups is to find out how you each experience and perceive your role and where you see it going in the future.

3. Ground Rules

There are no right or wrong answers in this focus group, only differing points of view. I encourage you to share your point of view even if it differs from what others have said. Please also feel free to share negative comments as they are just as important as positive ones.

Please note that we are making an audio recording of this session to ensure that we don't miss any of your comments. We can't write fast enough to record all of your contributions by hand and don't want to miss anything. Please allow just one person to speak at a time as a matter of courtesy and to aid accurate transcription of the recording. You have been asked to wear name tags so that we may all refer to each other by name however names will not be used in any of our reports and your confidentiality is ensured. Please also turn your mobile phones to silent and if you need to take a call, please leave the room with minimal disruption to the group.

4. Questions

To get started we might quickly go around the room and introduce ourselves and state where we are from.

Let's start with a broad question….

Current	
1.	Is it important for women with gynaecological cancer to have access to a specialist nurse?
2.	What is the most important aspect of your role?
3.	When do you think women with gynaecological cancer need to see a specialist nurse?
5.	Have you faced challenges in negotiating your role within the treatment team?
6.	What are your sources of professional support?
7.	Can you tell me what you like and dislike most about your role?
Future	
8.	How would you like to see the specialist nurse role in gynaecological oncology develop in the future?
10.	What suggestions do you have for improving education for specialist nurses in gynaecological oncology?
11	Would a model of care or other document such as best practice guidelines be beneficial to specialist nursing practice in gynaecological oncology in Australia or New Zealand?

5. Conclusion

To conclude, we have covered ……, ……., ……. Is there anything further you would like to add? Is there anything you feel we have missed?

Appendix IX Interview schedule

Interview schedule

The overall aim of this study is to determine how specialist nurses in Australia and New Zealand contribute to the care of women with gynaecological cancer and what the role means within the context of gynaecological cancer care within Australia and New Zealand now and into the future. Specifically, this study aims to:

7. Describe what specialist nurses do in their role of caring for women with gynaecological cancer in Australia and New Zealand
8. Determine how specialist nurses and other members of the gynaecological oncology treatment team experience and perceive the specialist nurse role.
9. Make recommendations for a model of specialist nursing care for women with gynaecological cancer.

Individual interviews are aimed at capturing the experiences and perceptions of specialist nurses in regard to their role of caring for women with gynaecological cancer. The interviews will allow the nurses to give an individual perspective if they also participated in a focus group or share information that they may not have felt comfortable sharing within the focus group. Individual interviews also offer specialist nurses who will not be in attendance at the conferences the opportunity to make a contribution. Specialist nurses working in a variety of settings will be sought for interview to ensure maximum variation in data and true representation of the population.

Interview Schedule

6. Introduction

Establish rapport and introduce self. My name is Olivia Cook and I am a PhD candidate from Monash University School of Nursing and Midwifery, Peninsula Campus. Thank you for taking the time to share your experiences and expertise with me today.

7. Purpose

The overall aim of this study is to determine how specialist nurses in Australia contribute to the care of women with gynaecological cancer and what the role means within the context of gynaecological cancer care within Australia and New Zealand now and into the future. The aim of this interview is to capture your experiences and perceptions as specialist nurse who cares for women with gynaecological cancer and determine how you see your role in the future. This and other interviews will complement a survey that you may have already completed (and if you have not already done so I encourage you to complete) considering what specialist nurses *do* to care for women with gynaecological cancer.

8. Audio recording, participation and confidentiality

With your permission I would like to audio-record this interview to ensure that I don't miss any of your comments. I will also be taking hand-written notes and if you do not wish this interview to be recorded, I will just take notes. I would like to remind you that you are not obligated in any way to participate in this interview and if you wish to withdraw your participation you are free to do so at any time. Your confidentiality will be maintained throughout the research process and the transcribed recordings will not be identifiable. [With the recorder turned on].. with your permission I would like to record this interview taking place on the ....(day) of ..... (month) of 2016 at .....am/pm. This is interview number.....

9. Questions

To get started it would be great if you could share some background on your role and the women that you care for....

The interview will then follow this semi-structured approach.

Current	
1.	Is it important for women with gynaecological cancer to have access to a specialist nurse?
2.	What is the most important aspect of your role?
3.	When do you think women with gynaecological cancer need to see a specialist nurse?
5.	Have you faced challenges in negotiating your role within the treatment team?
6.	What are your sources of professional support?
7.	Can you tell me what you like and dislike most about your role?
Future	
8.	How would you like to see the specialist nurse role in gynaecological oncology develop in the future?
9.	What do you understand about the credentialing of specialist nurses in Australia?
10.	What suggestions do you have for improving education for specialist nurses in gynaecological oncology?
11	Would a model of care or other document such as best practice guidelines be beneficial to specialist nursing practice in gynaecological oncology in Australia?

10. Conclusion

To conclude, we have covered ……, ……., ……. Is there anything further you would like to add? Is there anything you feel we have missed?

Thank you for your time and willingness to share your experiences today. You have made a very valuable contribution to this research. I will be in contact once the interview has been transcribed and provide you a copy of the transcription for you to verify.