# Australian Journal of Cancer Nursing

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# Editorial

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Welcome to the latest issue of the *Australian Journal of Cancer Nursing*. Like both of us, you may be surprised by just how quickly time seems to fly; we are now starting to think about the end of year and, hopefully, some warmer and drier weather.

As we have transitioned from the past 2 years of pandemic-imposed restrictions we find ourselves busier than ever, but very pleased that things are starting to return to 'normal' with face-to-face meetings and conferences back on the agenda. We both attended the CNSA Annual Congress in Brisbane in June, and it was great to meet many of you who were also there.

We would like to take the opportunity to say thank you to readers who have submitted manuscripts to the journal throughout the year and to all of our peer reviewers. Despite their busy lives, our peer reviewers volunteer their time for this important work, without which this journal would not be possible.

Our guest editorial for this issue has been written by one of our Editorial Board members Diane Heart. The editorial focuses on improving patient access to clinical trials in regional Australia, which we know is an issue of both great importance and relevance to many readers.

The Editors,
Jacqueline Bloomfield and Karen Strickland

# Guest editorial
# Improving Patient Access to Clinical Trials in Regional Australia

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Hello *AJCN* readers, my name is Diane, I am a registered nurse and I work as a clinical trials coordinator. I am delighted to be invited to write a guest editorial for CNSA because it gives me the opportunity to talk about my work, why I love this area of nursing and explain in a little more detail what opportunities clinical trials hold for cancer patients facing life limiting disease. I would like to begin by covering the basics and talk about what a clinical trial is, broadly discuss some of the issues such as patient accessibility and how clinical trials improve patient outcomes and, most importantly, explain what you the nurse can do to assist patients to make informed treatment choices.

Clinical trials are research studies that test and evaluate new medications, surgical interventions, radiological procedures and medical devices; they are an important area of nursing because they extend treatment choices when conventional options have been exhausted. Clinical trials innovate healthcare delivery by allowing healthy participants to meaningfully participate in the discovery of new treatments that either improve quality of life or prolong or find new interventions to eliminate illness and disease completely.

Clinical trials were previously only accessible to people living in metropolitan areas, resulting in inequitable access to innovative healthcare to those living in regional areas. Some clinical trials require more interventions, including immunotherapy or targeted systemic treatments designed to shrink cancers before surgical intervention. This type of clinical trial requires an impatient facility and, therefore, is inaccessible to people living in remote regional communities[1]. However, due to advances in technology and the introduction of telehealth, some clinical studies can be carried out remotely, effectively improving access and reducing demographic disparity[2]. Increasing the establishment of medical facilities and multidisciplinary care at sites removes the travel burden by treating patients locally. Additionally, increasing site locations increases the use of telecommunications to improve access to specialist consultations and clinical trial data collection efficiency[3].

COVID-19 alerted the world to testing, monitoring and evaluating medications which, in some respects, was a great thing because it got people thinking about the processes of medication development, raising the profile of clinical trials, and leading to the development of regional centres. An example of this is the Regional Trials Network Australia (RTNA) based in Victoria which offers the first regional based clinical trials network and aims to bridge the gap in cancer outcomes between rural and metropolitan cancer patients[3]. In 2016, the rate of cancer trial participation was 6.7% in metropolitan Melbourne, but only 1.2% in regional Victoria. The RTNA identified patients who participated in clinical trials had a 5% increase in survival rate compared to patients who did not[3].

Improving health service provision in rural areas is an issue of national importance and one that all cancer nurses should be aware of. Research shows that cancer patients living in regional areas have a 5% decrease in survival rate following a cancer diagnosis than metropolitan patients, simply due to geographical location, accessible healthcare and treatment options[4]. Between 2010 and 2020, there was a 7% higher mortality rate or about 9,000 additional rural deaths per year compared to urban counterparts[5]. Another report by Chua et al.[6] stated that between 2011 and 2015, 180.4 people per 100,000 individuals living in regional locations died from cancer compared to 157.8 per 100,000 in urban locations[6].

Nurses make up the largest cohort of health professionals and we are the ones that have the most direct patient care. It's therefore up to us to advocate for our patients and lobby for better access to affordable, innovative healthcare accessible to all regardless of demographic.

I hope cancer nurses reading this short piece have been enlightened and I hope that perhaps, during appropriate consultation with cancer patients, you might feel confident to suggest participating in a clinical trial which may extend patient options as well as contribute to finding better treatments for the cancer patients that follow.

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Cancer Nurses Society of Australia

# A nursing primer: immunoglobulin (Ig) therapy for secondary antibody deficiency (SAD) in haematological malignancies

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## Abstract

Immunoglobulin (Ig) therapy is increasingly being used for secondary antibody deficiency (SAD) in cancer patients with haematological malignancies. The aetiology of SAD can be attributed to the underlying condition or to the expanding range of treatments now available that target the immune system. Most often, immunodeficiency is clinically diagnosed as hypogammaglobulinaemia in patients with haematological malignancies and results in these patients being at a greater risk of acquiring an infection. The administration of Ig therapy to improve immunity in these patients has traditionally been intravenous and in hospital. However, subcutaneous Ig therapy is an innovative and alternative approach that can be more widely implemented in cancer centres and has the potential to allow home self-administration. This article reviews current Ig practice in adults with SAD and the subsequent implications on nurses and patients in Australia.

## Introduction

### Subcutaneous treatment

Australian cancer nurses administer intravenous immunoglobulin (Ig) therapy to a varied population of patients either as in-patients or in ambulatory centres[1]. These infusions are often prescribed to treat primary or secondary antibody deficiencies (SAD)[1]. In Australia and New Zealand, 89% of haematologists initiate Ig therapy for SAD in patients with haematological malignancies[2]. Increasingly, subcutaneous Ig therapy is being instituted in Canada, Europe and the United States of America as a viable option for patients with SAD[3]. Evidence shows that subcutaneous Ig therapy results in fewer in hospital stays, more stable serum Ig levels, lower infection rates and few adverse reactions[1,4–6]. The use of subcutaneous Ig therapy provides many opportunities to improve the quality of life of patients with SAD. For nurses and patients, subcutaneous Ig therapy provides a more patient-centred approach for the treatment of SAD in haematological malignancies that is both acceptable and economical for patients and healthcare systems.

### Secondary antibody deficiency

SAD is caused by many haematological malignancies including chronic lymphocytic leukaemia (CLL), multiple myeloma (MM) and non-Hodgkin lymphoma (NHL)[7,8]. Other types of SAD exist and occur as a result of therapies that directly or indirectly target B cells, otherwise known as B lymphocytes[8,9]. As a vital part of the immune system, B lymphocytes produce antigen-specific Ig to fight invasive bacteria and viruses[7]. When B lymphocytes are unable to produce Ig, patients present with hypogammaglobulinemia. This occurs in approximately 85% of CLL and 83% of MM patients[10]. Clinically, hypogammaglobulinemia is defined as a low serum Ig level of less than 4g/L[10–14]. The increased use of B lymphocyte-targeted therapies such as rituximab, often prescribed as maintenance therapy or in combination with chemotherapy, together with extended steroid use, has resulted in more patients experiencing SAD[7,8]. Therefore, immune deficiencies in these patients caused by the underlying disease and/or the pharmacological agents used for the treatment of these diseases increases the risk of patients acquiring infections. Infections in patients with haematological malignancies are

usually recurring and attributable to encapsulated bacteria affecting the respiratory tract[7]. Examples include *Streptococcus pneumoniae, Klebsiella* and *Haemophilus influenza*[10]. On average, mortality rates due to infection in CLL and MM patients are 50% and 22% respectively[10].

### Assessment

To reduce the burden of infection in cancer patients, patients with haematological malignancies at risk for SAD require specific clinical and laboratory assessments as well as screening for risk factors[7,10]. Identifying patients who have had or who are receiving chemotherapeutic agents that cause prolonged immunosuppression such as cyclophosphamide or fludarabine necessitates more regular monitoring of serum Ig levels[8]. Additionally, patients who present with a history of severe and frequent infections, including bronchiectasis, also warrant more frequent monitoring[8].

The evaluation of serum Ig levels, vaccination responses and lung function tests can also help identify high-risk patients[8]. Pathology tests, including full blood count, and liver and renal function tests, should also be performed to identify high-risk and low-risk patients[9]. Neutropenia and lymphopenia, identified from a full blood count, indicates the patient is at high risk of infection. While liver and renal function tests, which show protein loss associated with the renal and/or gastrointestinal tract, can identify patients who are low risk[9]. Hence, reviewing the patient history, and assessing the clinical, laboratory and relevant risk factors in those with CLL, MM and NHL, can identify those who may benefit from Ig treatment.

### Treatment

In cancer patients with haematological malignancies, treatments to manage SAD and mitigate the risk of infection include prophylactic vaccination, prophylactic antibiotics and Ig therapy[8]. Many studies report the commencement of Ig therapy in those with SAD in the context of haematological malignancies using serum Ig levels and infection history as criteria for the initiation of treatment. In studies of haematologists, immunologists and other specialised physicians, 81–89% stated that they initiated Ig therapy for severe hypogammaglobulinemia (Ig <4g/L) and severe infections[2,3–11]. In a larger retrospective study by Legendre et al.[12] conducted between 2012 and 2013, Ig therapy was commenced, in patients diagnosed in CLL, MM and NHL, where the Ig threshold was (Ig <5.7g/L). Of these 74.5% of patients had a history of infection. Additionally, in a cross-sectional study by Benbrahim et al.[13], it was found that Ig therapy (initiated at a threshold of Ig <5g/L), resulted in no infections in more than half of the patients (n=231), from a median of two in the 12 months previous to commencing Ig therapy. These results have led to national guidelines on the use of Ig therapy, where SAD is associated with hypogammaglobulinemia and infection history or severe infection[14].

### Current evidence-based guidelines for Ig therapy

Guidelines for the use of Ig therapy vary worldwide. In Europe, intravenous and subcutaneous Ig therapy is supported by the European Medicines Agency (EMA)[3,8]. The current guidelines state that intravenous and subcutaneous Ig therapy can be administered to CLL and MM patients or to patients who have undergone allogeneic hematopoietic stem cell transplantation[3]. More specifically, inclusion criteria also include patients "who suffer from severe or recurrent infections, ineffective antimicrobial treatment and either proven specific antibody failure (PSAF) or serum IgG level of <4g/l"[15]. In Australia, the National Blood Authority recommends intravenous and subcutaneous therapy for a wide range of haematological malignancies, including acute leukaemia, CLL, MM, NHL and post-haemopoietic stem cell transplantation (HSCT)[14]. To be eligible, patients must present with severe hypogammaglobulinaemia (Ig <4g/L), or serum Ig more than 4g/L with a 12-month history of one or more severe infections, or serum Ig more than 4g/L with a 6-month history of two or more severe infections that are unresponsive to antibiotic treatment[14]. Overall, most guidelines suggest that Ig therapy for SAD in haematological malignancies is indicated for selected patients with hypogammaglobulinaemia and infection[8].

## Ig therapy

### Administration and dosing

Generally, intravenous Ig therapy is administrated at 200–400mg/kg every 3–4 weeks[16]. When administrating subcutaneous Ig, the conversion from intravenous to subcutaneous administration is 1:1 based on patient weight[16]. The total monthly dose, calculated in grams, is then divided into weekly doses of higher immunoglobulin G (IgG) concentrates of 20% (10% used for intravenous infusions)[16,17]. Given that subcutaneous tissue only allows for a small volume to be administered at one time, subcutaneous Ig therapy needs to be infused more frequently and at a higher concentration compared to intravenous dosing schedules[17,18]. This results in more stable serum IgG levels, fewer adverse events and a decreased risk of infection[16,18].

Currently, in Australia, Hizentra and Cuvitru 20% are the two products available for subcutaneous Ig therapy[14]. There are three methods to administer subcutaneous Ig therapy; subcutaneous administration sites are demonstrated in Figure 1. The first method uses a battery operated or gravity infusion pump to administer the product at a controlled rate[16]. Infusions are set at specific intervals, but are most often administered weekly[16]. The second method is commonly known as the 'rapid push' technique[16]. This technique allows the user to administer their Ig dose without a pump, using an infusion set, syringe and 23–25-gauge needle. The main difference between these two techniques is that the rapid push technique allows the individual to draw up their total individualised dose into smaller quantities that can be administrated more than once a week[19].

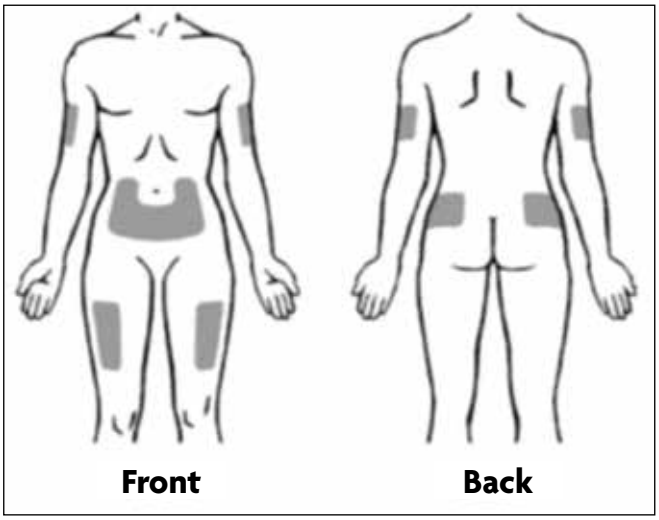


*Figure 1. Subcutaneous administration sites*[20]

The third method, called facilitated subcutaneous immunoglobulin (fSCIg) therapy, is a relatively new method. For fSCIg the dosing conversion is the same as for rapid push or pump infusions[18]. It involves subcutaneous administration of a recombinant human hyaluronidase (rHuPH20) prior to administration of Ig. The molecule catalyses the breakdown of hyaluran, causing higher amounts of IgG to be delivered into subcutaneous tissue[17,18]. Consequently, infusions can be administered at three to four weekly intervals using lower concentrations[17,18].

## Subcutaneous Ig therapy: efficacy and safety

### Serum IgG levels and infection rates

Several studies have evaluated serum IgG trough levels of intravenous and subcutaneous Ig therapy and the incidence of infection. In a 2017, prospective, randomised, controlled non-blinded study by Vacca et al.[5] investigated the efficacy of subcutaneous Ig administration in a population of MM patients with SAD over a median period of 18 months. In this study, in the subcutaneous group serum IgG levels remained stable, between 8.3–9.5g/L, compared to the intravenous control arm which reported IgG levels of 2.4–5.2g/L. Furthermore, both the number of infections and the severity of infections were significantly lower ($p<0.01$) in the subcutaneous group[5]. A large prospective study by Reiser et al.[4] on the management and outcomes of SAD in CLL, MM and NHL patients also found that median serum IgG levels remained stable (Ig >5g/L) when the administration of Ig therapy was subcutaneous. However, this study did not find a statistically significant ($p=0.060$) difference in IgG serum trough levels between the groups. However, in 82% of patients receiving subcutaneous therapy, the overall rate of infection decreased by 21% after 1 year. These studies indicate that subcutaneous Ig therapy is comparable if not superior to intravenous Ig therapy in maintaining serum IgG levels and preventing infections.

A more recent retrospective study by Cinetto et al.[6] also examined the efficacy of subcutaneous Ig therapy. Of patients (n=131) with SAD associated with CLL, MM and NHL, 99 received subcutaneous Ig therapy and 32 switched from intravenous to subcutaneous therapy[6]. Over a median period of 12 months higher serum levels were observed in those who switched from intravenous to subcutaneous therapy, and the number of infections decreased from 375 to 109[6]. Similar results were also found in a retrospective study by Windegger et al.[1], whereby serum IgG levels were assessed in 30 SAD patients with CLL, MM and lymphoma on intravenous and subcutaneous Ig therapy; 17 patients received subcutaneous Ig therapy only and 13 patients transitioned from intravenous to subcutaneous Ig therapy. Over the 3-year period both median serum levels were consistently higher (Ig >7.5 g/L) in those who received subcutaneous Ig therapy compared to those patients who commenced on intravenous Ig therapy before switching (Ig >7.0g/L)[1]. Whilst the efficacy of subcutaneous therapy is clear in the studies of Reiser et al.[4], Vacca et al.[5] and Cinetto et al.[6], Windegger et al.'s[1] results point to the clinical benefit of using long-term subcutaneous Ig therapy in selected patients.

For fSCIg therapy, studies involving primary antibody deficiency the efficacy and safety of this treatment has been found to be equivalent to intravenous administration[18,21]. Few studies have examined fSCIg therapy in SAD of patients with haematological malignancies[17]. One such retrospective study, by Dimou et al.[17] of CLL, MM, NHL and Hodgkin's lymphoma patients with SAD (n=33) treated with fSCIg as per the European Society for Medical Oncology (ESOM) guidelines, examined efficacy and safety of fSCIg therapy. During the study period (mid-October 2015 and mid-January 2018), serum trough levels remained above ESMO recommendations and the infections rates were comparable to intravenous Ig therapy[17]. When fSGIg doses were adjusted and infusion intervals reduced, the rate of infection further decreased. Clinically, fSCIg therapy is shown to be just as efficacious as the rapid push or pump methods of infusion, and therefore offers an additional administration option for patients with long-term illness[17].

### Serum IgG levels and adverse reactions

Intravenous infusion-related reactions, including backache, dyspnoea, fever, flushing, headache, haemolysis, myalgia, nausea, vomiting, tachycardia and pruritis, are thought to occur as a result of rapid peaking of serum IgG levels[22]. While these adverse events can be managed by health professionals as they occur, for a cohort of patients, additional premedication with antihistamines or intravenous hydration may be required, particularity if the patient has a history of thrombotic or renal complications[22]. As such, administration and monitoring of intravenous Ig infusions can only occur in the clinical setting, e.g. a day therapy unit. Studies of subcutaneous Ig therapy all concur that adverse events are negligible, indicating that subcutaneous Ig therapy is a safe option for patients preferring home-based treatment.

The study by Windegger et al.[1] is the most detailed patient-reported evaluation of adverse reactions in those receiving subcutaneous Ig therapy. The results describe adverse reactions in both subcutaneous and intravenous cohorts, but in the subcutaneous Ig therapy group adverse events were mild and did not require intervention[1]. Headaches, which are a common adverse event of intravenous Ig infusions, were reported in this study to decrease from 44% to 18% when patients switched from intravenous to subcutaneous Ig therapy[1]. Additionally, in the prospective study by Reiser et al.[4], no adverse reactions were reported in the subcutaneous arm (patient-reported questionnaires were completed by physicians)[4]. However, 11 non-serious and four serious adverse events requiring hospitalisation were reported in the intravenous arm which included allergic reactions, chills, back pain, nausea, pleuritis, dizziness and proctitis[4]. Similar adverse events have also been identified in the larger retrospective study by Legendre et al.[12]; although the total number of adverse events were minimal, patients still reported intravenous infusion reactions. Adverse events related to intravenous infusions not only lengthens hospital stays but is also detrimental to a patient's health and wellbeing.

The predominant adverse events related to subcutaneous Ig therapy are reactions at the site of infusion, including oedema, erythema and itching, all of which can be managed with over-the-counter antihistamines and analgesic medications[1,23]. These side effects are usually mitigated by ensuring that the injection site and equipment are dry[16]. Modifications to medication products and equipment supplies can also reduce the risk of local site reactions[16]. As highlighted in the above studies, subcutaneous Ig therapy has few severe complications requiring monitoring by clinicians or hospitalisation[14,16]. However, education of patients who are prescribed subcutaneous Ig therapy for home administration is paramount to achieving optimal patient outcomes.

## Subcutaneous Ig therapy: a patient-centred initiative

### Economic evaluation

An important advantage of subcutaneous Ig therapy is that this route allows patients to actively participate in their treatment and allows for treatment to occur in the home. While subcutaneous therapy can be ideal for some patients who travel long distances to treatment centres, the economic benefits to nursing resources are also many. The prospective study completed by Windegger et al.[24] examined the costs on healthcare systems and clinical patient outcomes of both Ig therapies over a 10-year period. In this study, using a simulation model, 13 patients with SAD received intravenous therapy in hospital every 4 weeks, and three subcutaneous infusions in hospital followed by home self-administration[24]. In this study, the total cost of intravenous Ig therapy on nursing time and wages was calculated to be A$151,511 and for subcutaneous therapy A$144,296[24]. However, although subcutaneous product and materials are more expensive, this cost is offset by decreased nursing time and wages, and treatment unit space[24].

A larger case study by Streu[23] focused on assessing nursing and patient outcomes connected to a pilot programme. This study included 36 CLL, MM and lymphoma patients with SAD who transitioned from intravenous to subcutaneous Ig therapy. Of the patients, only two switched back to intravenous therapy due to difficulties in dexterity and geographical isolation and their inability to access therapy-related resources[23]. Streu[23] conducted the study over 3 years and found that intravenous Ig therapy equalled 12 hours per year in nursing time. Subcutaneous therapy was found to decrease from 12 hours of nursing time to 6 hours of nursing time per year, as in-hospital training and monitoring gradually reduced over time[23]. In an Australian study, patients on subcutaneous Ig therapy had three training sessions, each averaging 2.5 hours, that also decreased over time as competency in self-administration increased[1]. Hospitals and nurses face increasing challenges in providing high quality care that is cost effective; fortunately, both the studies by Windegger et al.[1] and Streu[23] demonstrate the economic advantage of subcutaneous Ig therapy over intravenous Ig infusions.

Besides demonstrating the nursing hours saved and the reduced impact on treatment (day unit) space, both studies also illustrate how the role of the cancer nurse is changed as new treatment options evolve. Instead of nurses managing intravenous infusions and venous access sites, with subcutaneous Ig therapy nurses must be competent in educating, assessing and managing SAD patients transitioning to subcutaneous therapy[16]. In a cross-sectional study by Benbrahim et al.[13] of SAD in patients (n=231) with CLL, MM and lymphoma, Eastern Cooperative Oncology Group (ECOG) performance status was found to be lower in patients receiving intravenous Ig therapy. This study highlights the importance of assessing patients' eligibility and functional status for managing self-administered subcutaneous therapy in the home. Other considerations are health literacy levels of patients to ensure that patients are proficient in trouble-shooting any potential problems, and also the inclusion of education and assessment of the family members or carer in cases where patients are unable to self-administer but still prefer to receive treatment at home[23].

In a Canadian study, patients were trained by the clinical nurse specialist from the CancerCare Manitoba unit[23]. In the Australian study by Windegger et al.[1], all participants were trained to self-administer via a structured training program delivered at the Sunshine Coast Hospital and Health Service centre in Queensland. On average, the number of training sessions necessary to reach proficiency was three[1]. It is clear in both studies that standardisation of training programmes of home self-administered subcutaneous therapy must be in place to maintain the efficacy and safety of the therapy. For this reason, the Australian Blood Authority has produced a generic training checklist that nurses can use when assessing patient eligibly, and

online Ig e-learning modules targeted towards nurses who are involved in the administration of intravenous and subcutaneous Ig products and follow-up of patients receiving Ig products[14]. Patient resources are also standardised, with the Australian Blood Authority providing a patient information brochure and a patient diary to record treatment infusions[14].

### Patient and family perspectives

Apart from the economic advantages of subcutaneous Ig therapy on healthcare systems, the benefits to patients who do not need to visit healthcare institutions are many – they are able to save time on transportation, parking costs and avoid exposure to healthcare-associated infections[16]. In studies where patients are receiving subcutaneous Ig therapy, patients reported higher levels of satisfaction as there is less intrusion on their daily lives, therefore improving their quality of life. In the study by Windegger et al.[1], patient satisfaction with subcutaneous Ig therapy was evaluated using a specific questionnaire rated on a 5-point Likert Scale. Of the participants, 93% of patients reported the training programme and nursing support as 'very good', and 75% stated their quality of life improved when transitioning to subcutaneous therapy. Vacca et al.[5], in their slightly larger study, evaluated subcutaneous Ig therapy on quality of life more extensively using the 36-item short form health survey. The findings reported improved levels in patient wellbeing and subsequently increased involvement in their own and family's activities[5]. The increased autonomy and patient involvement that subcutaneous Ig therapy allows, coupled with more stable serum IgG levels, may also be factors that result in fewer hospitalisations compared with intravenous therapy[16]. A more patient-centred approach has the potential to lead to increased satisfaction with care and better treatment adherence[16].

### Pump verses rapid push

Whilst the majority of studies comparing methods of administration have been undertaken in patients with primary immunodeficiency, these studies reflect patients' perspectives on reasons for choosing a specific method of administration. Bienvenu et al.[19], in a randomised crossover study of patients with primary immunodeficiency, compared rapid push and pump-infused subcutaneous Ig therapy. Of the 28 participants who completed the study, 19 preferred the pump. One reason cited was the difficulty in pushing the plunger due to the viscosity of the product[19]; Figure 2 details the equipment required for pump infusion[25]. Conversely, in a randomised crossover study by Warnatz et al.[26], of the 28 participants who completed this study, 34.5% preferred the rapid push technique due to the total reduced time in product delivery. Additionally, in a study by Sharpio et al.[27], parents of paediatric patients reported preference for the pump, particularly where children were old enough to be distracted by visual technology. However, the rapid push technique was favoured in children younger than two due to the difficulty in keeping them still[27].

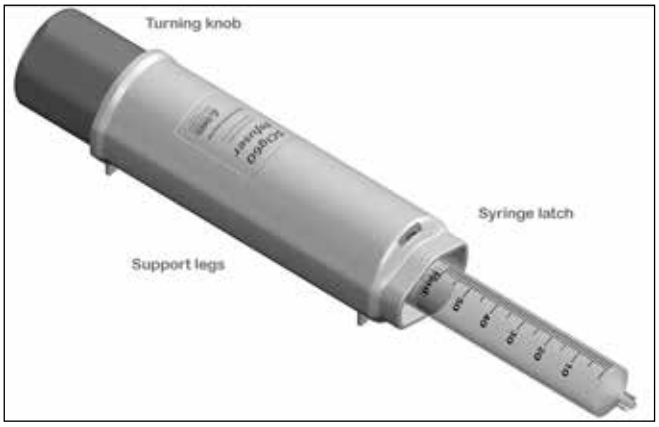


*Figure 2. A subcutaneous spring-operated infusion pump[25]*

### Contraindications to and considerations for subcutaneous Ig therapy

Although studies have shown the benefits of subcutaneous therapy, the therapy may not be appropriate for all individuals. For instance, parents of young paediatric children may feel too uncomfortable to administer subcutaneous infusions, or patients who are visually impaired or are physically restricted in some way may not have the agility to manipulate the equipment to self-administer[16,23]. Comorbidities such as arthritis or depression may also impede one's ability to safely inject[23]. Depending on the country, patients may incur ongoing pharmacy-related costs, drug-related costs and administration costs which they are unable to afford[28]. In a study by Runken et al.[28], between 2011 and 2013 patient insurance claims were analysed from the national healthcare claims database in the United States of America. Of, 1639 patients with primary antibody deficiency, the overall costs of subcutaneous Ig infusions were higher compared to those who received intravenous infusions. Fortunately, in Australia, Ig products are subsidised and pumps are provided at no cost to the patient, enabling patient accessibility to subcutaneous Ig therapy[24]. As such, although subcutaneous Ig therapy has many benefits, both intravenous and subcutaneous Ig therapy have their place in cancer services. The advantages and disadvantages of both methods are outlined in Table 1.

## Recommendations

As patient-centred care is now recognised as a National Safety and Quality Health Service standard, home self-administrated subcutaneous Ig therapy is recommended for the treatment of SAD in haematological malignancies as this is able to meet individual patient needs and improve their health and wellbeing. At present, many healthcare institutions are participating in the national home self-administrated subcutaneous Ig therapy programme[14]. Future pilot programmes that examine real life data, similar to the study by Streu[23], would be beneficial to strengthen the evidence for this innovative approach to Ig therapy.

## Conclusion

This review demonstrates that Ig therapy is an appropriate

*Table 1. Comparison of Ig subcutaneous and intravenous therapy*[29]

| Advantages | Disadvantages |
|---|---|
| **Subcutaneous Ig therapy** | |
| • Home-based therapy.<br>• IV access not required.<br>• More consistent serum IgG levels.<br>• Decreased risk of infections.<br>• Equipment is portable: patients can take their treatment to the office or on holidays.<br>• Increased quality of life. | • Requires frequent infusions if using the rapid push method.<br>• Local adverse events.<br>• If using a battery-operated pump equipment repair may be difficult in remote and rural regions. |
| **Intravenous Ig therapy** | |
| • Ideal for patients who have physical limitations or comorbidities. | • Hospital-based.<br>• Requires intravenous access.<br>• Requires medical monitoring.<br>• Risk of systematic events.<br>• Wearing off of serum trough levels. |

interventional management strategy for cancer patients with SAD. Given the efficacy and safety of the data presented, subcutaneous Ig administration is a viable option for cancer patients with SAD associated with haematological malignancies inclusive of CLL, MM and NHL. By changing administration methods of Ig therapy from intravenous to subcutaneous in cancer patients with SAD, nursing workflow can be streamlined and productivity can be increased. Additionally, patient satisfaction and wellbeing may increase. By giving selected patients a choice about what Ig treatment method they prefer and educating them appropriately, cancer nurses empower patients to make informed decisions about their own care.

## Conflict of interest

The author declares there are no conflicts of interest.


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# Concurrent chemotherapy and radiation therapy for anal cancer: quality of life evaluation to improve person-centred care

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## Abstract

**Background** Chemoradiation therapy is the standard protocol to treat anal cancer, with often severe toxicities.

**Objectives** This study explored patients' responses to quality of life (QOL) issues and dispositional optimism during treatment for anal cancer.

**Methods** A longitudinal study assessed QOL, anal-specific issues and disposition. Data was collected at the end of treatment and at 3 months following; analysis by SPSS Version 27.

**Results** Twenty-one participants completed the surveys. There was a significant increase in QOL (p=.022) and overall health (p=.007) at 3 months post-treatment, as well as fatigue (p=.012), appetite loss (p=.002), pain (p=.044) and urinary frequency (p=.011). Several symptoms showed no significant change at T2. Results showed moderate optimism at T1 but high pessimism at T2.

**Conclusion** Reduced function remained in a range of dimensions at T2, as well as increasing pessimism.

**Implications for practice** Multidisciplinary interventions are needed to support these patients during and beyond treatment.

## Background

Anal cancer is considered a relatively rare disease, affecting approximately 591 people in 2021 in Australia[1]. However, the incidence has more than doubled in the last 20 years, particularly among women[2,3]. Approximately 80% of cases are squamous cell carcinoma (SCC), which starts in the cells lining the anal margin and anal canal. The exact cause of anal cancer is unknown, but there is a known association between anal cancer and HPV infection, with risk increasing with age[1]. Historically, surgery such as abdominal perineal resection was the mainstay of treatment[4] but modern treatments combine radiation therapy and chemotherapy consisting of IV Mitomycin C and 5-Fluorouracil as the standard protocol[2]. Potential complications include radiation enteritis, diarrhoea, proctitis, skin desquamation, strictures, sexual dysfunction, dyspareunia, pelvic fractures, induced menopause, faecal incontinence, and urinary tract dysfunction[5–7]. Clinician-reported acute toxicities have been as high as 80%, and late effects reported at approximately more than 10%[8,9]. To date, despite improvements in radiation technologies, such as intensity modulated radiation therapy (IMRT)[10] radiation dose has been identified as a significant factor in radiation-induced toxicities[8,9].

Patients undergoing concurrent chemotherapy and radiation therapy for anal and perianal cancer have been evaluated for quality of life (QOL) issues at different time points. One study assessed the utilisation of IMRT with concurrent IV Mitomycin C and 5-Fluoruracil, showing that IMRT was effective in sphincter preservation, resulting in lower rates of acute grade 3+ haematologic, gastrointestinal (GI) and genitourinary (GU) toxicities compared to conventional radiation therapy techniques[10]. Das et al.[11] evaluated long-term QOL in patients undergoing definitive radiotherapy or chemoradiation therapy for SCC of the anal canal. They found that, at a minimum of 2 years post-treatment, these patients had acceptable QOL scores but poor sexual functioning scores – median interval from treatment to survey was 5 years (range 3–13 years). Sodergren et al.[9] systematically reviewed QOL issues with chemoradiation for anal cancer, and found relatively few studies of QOL, with formal QOL assessment generally absent from randomised controlled trials.

Joseph et al.[12] assessed patient-reported QOL after helical IMRT-based concurrent chemoradiation of locally advanced anal cancer utilising the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaires (QLQ), specifically the EORTC QLQ-C30 and colorectal QLQ-CR29 modules. These authors found that all QLQ-C30 functional symptoms were impaired at end-of-treatment but recovered by the 3 months follow-up, except for emotional and cognitive functioning. Also that the majority of symptom scores were worse at the end of treatment but had recovered by 3 months except for faecal incontinence, diarrhoea, urinary incontinence and dyspareunia. These symptoms persisted, with faecal incontinence returning to baseline at 12 months, while diarrhoea, urinary incontinence and dyspareunia persisted beyond that time.

Sterner et al.[13] conducted a systematic literature review of anal QOL studies and found that bowel function, urinary function and sexual function were negatively affected. These authors concluded that it may be important to evaluate QOL and body functions before treatment in order to identify patients at risk and provide appropriate information early in the post-treatment period to improve their QOL. Dapper et al.[14] compared long-term QOL in patients treated with IMRT versus 3D-conformal radiation therapy utilising the EORTC QLQ-30 and EORTC QLQ-ANL27 scales. Significant differences were observed in global QOL with a score of 81 in IMRT and 70 in 3D-RT, and also for fatigue and insomnia. The EORTC QLQ-ANL27 scale showed IMRT had significantly better bowel function scores for patients without stoma and also female sexual function scores. The symptom scales showed significant improvements in the mean scores for pain, urinary frequency, proximity to toilet and planning activities in favour of IMRT.

Another aspect of QOL to impact wellbeing may be financial toxicity. This may impact patients' QOL when undergoing treatment for cancer, independent of site treated, causing heightened stress for both the patient and the family[15].

Arraras et al.[16] developed a questionnaire specific to patients undergoing treatment for anal cancer. Many previous studies had utilised colorectal measures when assessing QOL for anal patients[10,11,17]. Arraras et al.[16] had found that many patients reported difficulties in obtaining the information they wished to receive, especially on specific areas such as sexuality. In a systematic review of preparatory information before chemoradiation, Waller et al.[18] found high acceptance of preparatory information with improved psychological outcomes and QOL. Several organisations provide specific information about anal cancer for patients[19]. Unfortunately, many health professionals may have limited experience in managing the myriad of symptoms and side effects these patients experience pre-and post-treatment.

Disposition, either optimism or pessimism, has an effect on QOL. Dispositional optimism (DO) has been studied in relation to managing a health crisis, such as cancer[20]. A correlation between DO and QOL was found to be positive[21]. Scheier et al.[22] suggested that DO impacts patients favourably for physical and psychological wellbeing when undergoing challenging life events. These authors found that when information is tailored to patients' dispositional differences it may influence how they respond to interventions to help them cope with treatment. The individual difference variables, optimism or pessimism, may determine the type of support and information that might be effective. Johnson[23] tested two informational interventions for patients receiving radiation therapy – for those with dispositional pessimism they focused on a description of the concrete objective aspects of the impending experience, and for those with DO, they included instructions in coping and self-care. Hirsch et al.[24] utilised the Life Orientation Test – Revised (LOT-R) to evaluate its psychometric properties in treated opiate-dependent individuals. Findings supported the measure to assess positive cognitive and emotional attributes that can be used to improve strategies for these patients in the type of information provided.

### Aim of the study

This study explored 1) patients' self-reported responses to QOL issues during and following chemoradiation for anal cancer; 2) patients' perceptions of information provision about managing the side effects of the treatment during and following treatment; and 3) whether disposition influences perceptions of QOL and the information received.

## Methodology

This is a longitudinal survey design undertaken at radiation oncology, Princess Alexandra Hospital, Brisbane (two departments) from September 2017 until the last patient was recruited in December 2019. The survey incorporated validated instruments by the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaires

(QLQ). The modules of the EORTC are used with permission: the EORTC QLQ-C30 (core scale)[25]; the EORTC QLQ-ANL27[9], the anal specific module, and the EORTC QLQ-INFO25[16], a questionnaire exploring information received about the disease and the treatment. The LOT-R[22] assessed areas of DO and dispositional pessimism. Surveys were administered in the penultimate week of treatment (usually the 4th or 5th week dependent on the prescription), and at 3 months post-treatment via a mailed questionnaire. Written comments were encouraged from the participants (PI). MOSAIQ[25] is the radiation oncology information system used in both departments, and recruitment was through accessing the contributing radiation oncologists' patient lists.

The radiation oncologist or a research nurse approached the patient regarding recruitment, and the patient was provided with an information sheet and a consent form. Once consent had been received, the first survey was provided prior to the penultimate week of treatment (T1). Prior to the second survey at 3 months after completing treatment (T2), the PI telephoned the participant to remind them the second survey would be arriving by mail with an enclosed stamped addressed envelope to return to the PI. Patient comments were 'themed' as exemplars for insight to the patients' thoughts only and were not qualitatively reviewed.

### Ethics

Ethical approval was provided by Metro South (Brisbane) Human Research Ethics Committee. Participating patients were at least 18 years old, able to read and write English sufficiently to understand and complete the surveys, and agreeable to receiving a telephone call from the research nurse prior to receiving the second survey.

### Instruments

This study utilised the EORTC QLQ-C30, the EORTC QLQ-ANL27, and the EORTC QLQ-INFO25 to assess QOL and information issues. The LOT-R assessed trait-like optimism and pessimism by assessing general dispositional responses[21].

The EORTC QLQ-C30 has been widely used in clinical trials research[27–29] and consists of 30 items on a scale of 1–4, where 4 is greater symptom distress. It includes five functional scales – cognitive, emotional, physical, role, and social functioning. There are three symptom scales, a global health scale, and additional symptoms. A high score equals high symptomatology. However, the single item measures ranged from 0–100 and, when summed a high score on the Global QOL scale, indicates a high QOL[26].

The EORTC QLQ-ANL27 is a supplementary questionnaire used with the EORTC QLQ-C30. The EORTC QLQ-AN27 consists of 27 items related specifically to patients with anal cancer undergoing treatment. It incorporates four multi-item scales to assess bowel function, pain or discomfort, sexual function, and stoma care. The EORTC QLQ-ANL27 uses the response categories of 1–4, where 1 = not at all, and 4 = very much. In addition, five single items assess frequent urination, keeping clean, proximity to toilet, lower limb lymphoedema, and planning activities. Two items on sexual functioning were reverse-scored.

The EORTC QLQ-INFO25 measures information received about the disease and the treatment. The EORTC QLQ-INFO25 uses the response categories of 1–4, where 1 = not at all, and 4 = very much. However, on this scale, a high score denotes a high level of satisfaction with information in all scales and items.

The LOT-R is a 10-item measure of optimism consisting of 10 statements scored on a 5-point Likert scale where 0 = strongly disagree to 4 = strongly agree; three items measure optimism, three items measure pessimism and four items are fillers. Three statements are negatively worded and reverse-scored.

A patient/consumer undergoing this particular treatment protocol was asked to complete the survey for readability, appropriateness and comfort. This patient completed the surveys and made comments, mainly how it felt going through this course of treatment, the information provided, and other issues. This person found nothing in the survey that was personally confronting from the survey. As a result, participants were encouraged to comment on any issues that they chose at both timepoints during the study.

### Data analysis

Data analysis was undertaken using the Statistical Package for the Social Sciences (SPSS) version 27[30]. Frequencies and percentages are reported for the patients' background categorical variables. Summed scores, means and any significant differences between variables were assessed between T1 (towards end of treatment) and T2 (3 months following treatment); paired samples t-tests investigated changes between all scales and subscales at these timepoints, with statistical significance set at $p \leq .05$. The confidence interval for all scales was set at 95%, and alpha was set at 0.05. Inferential statistics were undertaken to assess bivariate correlations of the four measurement scales and subscale using Pearson's correlation coefficient tests with correlation[1] significant at the 0.05 level and correlation[2] significant at the 0.01 level. Comments provided by the participants at both timepoints have been reported in full.

## Results

A total of 25 patients were approached to participate in this study over an 18-month period. Two patients refused and two consented but required admission, and were too unwell to proceed. This resulted in a final total of 21 participants. The majority of patients were female (71.4%), had completed secondary school (57.9%), lived at home with a spouse/partner (47.6%), and lived in their home during treatment (85.7%). Transportation to treatment each day was provided by a family member or friend (47.4%), and admission was required for 39.1%

of patients. The mean radiation dose was 54Gy over 30 fractions (daily treatments). All patients received concurrent IV Mitomycin and 5-Fluouracil (Table 1).

This study explored: patients' self-reported responses to QOL issues; patients' perceptions of information provision about managing side effects; and the influence of disposition on patients' perceptions of QOL.

### Patients' self-reported responses to QOL issues

The first aim of this study was to assess patients' self-reported responses to QOL issues during and following chemoradiation for anal cancer. The EORTC QLQ-C30 total scale showed no significant reduction in QOL at T2 (p=.198); however, overall health (single item) significantly improved by T2 (p=.007), and overall QOL (single item) significantly improved at T2 (p=.011) (Table 2). The five specific dimensions of the EORTC QLQ-30 (physical, role, emotional, cognitive and social functioning) all showed a slight, but non-significant decrease in T2 in three of four dimensions, with no real change in emotional functioning.

*Table 1. Demographic and medical variables*

| **Demographic variables** | | **n** | **%** |
|---|---|---|---|
| Gender | Male | 6 | 28.6 |
| | Female | 15 | 71.4 |
| Age | <40–60 | 11 | 47.8 |
| | 61+ | 10 | 43.5 |
| Lives with | Spouse/partner | 10 | 43.5 |
| | Family/friend | 6 | 26.1 |
| | Alone | 5 | 21.7 |
| Stay during treatment | Home | 18 | 78.3 |
| | Accommodation | 2 | 8.7 |
| | Staying friend/family | 1 | 4.3 |
| Admission during treatment | Yes | 9 | 39.1 |
| | No | 12 | 52.2 |
| Main support | Spouse/partner | 10 | 43.5 |
| | Family/friend | 9 | 39.1 |
| | Myself | 2 | 8.7 |
| Transport to treatment | I drove myself | 2 | 8.7 |
| | Family/friend | 10 | 43.4 |
| | Public transport | 3 | 13.0 |
| | Ambulance/community bus | 4 | 17.4 |
| Education | Secondary school | 11 | 47.8 |
| | Trade/Cert | 2 | 8.7 |
| | Tertiary | 6 | 26.1 |
| Site of cancer | Anal canal | 15 | 71.4 |
| | Anus | 6 | 28.6 |
| Dose of radiation | 43.2–54Gy | 15 | 43.2 |
| | 58–60Gy | 6 | 65.2 |
| Radiation fractions | 24–28 | 10 | 43.4 |
| | 30 | 11 | 47.8 |
| Chemotherapy | Mitomycin C / 5-Fluorouracil | 21 | 100 |

However, when reviewing specific items, fatigue significantly improved at T2 (p=.012), as did appetite loss (p=.002). The physical scale (PS) showed low mean scores (T1=190; T2=169, p=.111), as did dyspnoea (T1 and T2=1.76; p=1.00) and constipation (T1 and T2=1.53; p=1.00). Financial toxicity was reduced at T2 (T1=2.12; T2=188; p=.299) (Table 3).

The EORTC QLQ-ANL27 scale showed a non-significant decrease in anal-specific symptoms at T2 (p=.081) compared to T1. The total scales included 27 items, with three items related to female sexuality only and one item to male sexuality. Only one person reported a stoma (Table 4). There was a significant reduction in pain (p=.040), frequency of bowel movements (p=.011), and the need to be close to a toilet (p=.011) at T2. Urinary frequency was significantly reduced at T2 (T1=2.62; T2=1.93; p=.011). When assessing responses for anal-specific items, there was a significant improvement in pain and discomfort around the anal opening at T2 (p=.014). Unfortunately, four items showed no change at 3 months: frequent bowel movements (T1=2.62; T2=2.21; p=.929), problems with flatulence (T1=2.70; T2=2.70; p=1.00), urgency to move bowels, and feeling unable to completely empty bowels (T1=2.40; T2=2.50; p=.832). Sexuality was stratified into male and female cohorts, with no significance changes between timepoints. Several patients chose not to respond to these questions.

The EORTC QLQ-C30_1 significantly correlated with the EORTC QLQ-ANL27_1 (.650**, p=.003). The sexual subscales of the EORTC QLQ-ANL27_1 highly correlated between the male and female participants (>952**, p=.001); however, the cohort numbers were too small to make inferences. At T2 the sexual subscales were significantly correlated between the male and female participants (.972**, p=<.001), with male participants reporting a correlation between sexual issues and role function (.580*, p=.030) and social functioning (.553*, p=.040); female participants also reported correlations between sexual issues and role functioning (.630*. p=.016). Emotional function was positively correlated with cognitive function (.671**, p=.003), and the EORTC QLQ-ANL27_2 scale correlated significantly with role function (.590*, p=.013) (Table 5).

#### *Patients' written comments at the end of treatment (T1)*

***Theme: emotional***

> *(Person)... was intent on talking about my having a Will and health directive in place – seemed like a priority instead of focusing on how I was handling the overload of information. I understand they maybe have to do this but I was already in fight or flight mode!*
>
> *There were a few other things I didn't fully grasp but after the initial shock I think I heard only every other sentence – the rest was just noise.*
>
> *I realise I won't know if the disease is under control until the end.*

*Table 2. EORTC QLQ scale scores*

| Measurement scales | n | Items | Range | Mean | SD | Sum score | Corr | Sig |
|---|---|---|---|---|---|---|---|---|
| **EORTC QLQ-C30** | | | | | | | | |
| QLQ-C30_1 | 19 | 28 | 3 | 2.33 | .425 | 233 | | |
| QLQ-C30_2 | | | | 1.88 | .459 | 188 | .410 | .198 |
| **EORTC QLQ-C30 Overall health (global item)** | | | | | | | | |
| QLQ-C30 Overall health_1 | 17 | 1 | 6 | 3.70 | .771 | 370 | | |
| QLQ-C30 Overall health_2 | | | | 4.64 | 1.27 | 464 | .333 | .007 |
| **EORTC QLQ-C30 Quality of life (global item)** | | | | | | | | |
| QLQ-C30 Quality of life_1 | 17 | 1 | 6 | 3.76 | .831 | 376 | | |
| QLQ-C30 Quality of life_2 | | 1 | | 4.58 | 1.064 | 458 | .237 | .011 |
| **EORTC QLQ-ANL27** | | | | | | | | |
| QLQ-ANL27_1 | 17 | 27 | 3 | 2.34 | .446 | 234 | | |
| QLQ-ANL27_2 | | | | 2.10 | .565 | 210 | .485 | .081 |
| **EORTC QLQ-INFO25** | | | | | | | | |
| QLQ-INFO25_1 | 17 | 25 | 3 | 2.79 | .435 | 279 | | |
| QLQ-INFO25_2 | | | | 2.21 | .557 | 221 | .450 | .784 |
| **EORTC QLQ-INFO25 Overall health (global item)** | | | | | | | | |
| QLQ-INFO25 Overall_1 | 16 | 1 | 3 | 3.31 | .602 | 331 | | |
| QLQ-INFO25 Overall_2 | | | | 3.12 | .806 | 213 | .601 | .270 |

*Table 3. EORTC QLQ-C30 scale*

| EORTC QLQ-C30 scale | n | Items | Item range | Mean | SD | Total score | Corr | Sig |
|---|---|---|---|---|---|---|---|---|
| **EORTC QLQ-C30 functional scales** | | | | | | | | |
| Physical function_1<br>Physical function_2 | 17 | 5 | 3 | 1.90<br>1.69 | .480<br>.539 | 190<br>169 | .490 | <br>.111 |
| Role function_1<br>Role function_2 | 17 | 2 | 3 | 2.38<br>2.00 | .975<br>.775 | 238<br>200 | .022 | <br>.205 |
| Emotional function_1<br>Emotional function_2 | 17 | 4 | 3 | 2.01<br>2.04 | .407<br>.560 | 2.01<br>204 | .644 | <br>.783 |
| Cognitive function_1<br>Cognitive function_2 | 17 | 2 | 3 | 2.02<br>1.85 | .693<br>.723 | 202<br>185 | .475 | <br>.332 |
| Social function_1<br>Social function_2 | 17 | 2 | 33 | 2.29<br>1.97 | 1.016<br>.926 | 229<br>197 | .026 | <br>.340 |
| **EORTC QLQ-C30 symptoms** | | | | | | | | |
| Fatigue_1<br>Fatigue_2 | 17 | 3 | 3 | 2.88<br>2.33 | .716<br>.645 | 288<br>233 | .315 | .012 |
| Nausea/vomiting_1<br>Nausea/vomiting_2 | 17 | 2 | 3 | 3.24<br>2.71 | .831<br>.920 | 324<br>271 | -.149 | .120 |
| Pain_1<br>Pain_2 | 17 | 2 | 3 | 2.65<br>2.29 | .981<br>.830 | 265<br>229 | .385 | .170 |
| Dyspnoea_1<br>Dyspnoea_2 | 17 | 1 | 3 | 1.76<br>1.76 | .903<br>.664 | 176<br>176 | .432 | 1.000 |
| Insomnia_1<br>Insomnia_2 | 17 | 1 | 3 | 2.35<br>2.18 | .996<br>.883 | 234<br>218 | .931 | .455 |
| Appetite loss_1<br>Appetite loss_2 | 17 | 1 | 3 | 2.71<br>1.65 | .920<br>.702 | 271<br>165 | .023 | .002 |
| Constipation_1<br>Constipation_2 | 17 | 1 | 3 | 1.53<br>1.53 | .874<br>.874 | 153<br>153 | .346 | 1.000 |
| Diarrhoea_1<br>Diarrhoea_2 | 17 | 1 | 3 | 2.59<br>2.06 | 1.004<br>.966 | 259<br>106 | -.038 | .144 |
| Financial difficulties_1<br>Financial difficulties_2 | 17 | 1 | 3 | 2.12<br>1.88 | .857<br>.993 | 212<br>188 | .531 | .299 |

*Table 4. EORTC QLQ-ANL27 scale*

| EORTC QLQ-ANL27 scale | n | Items | Item range | Mean | SD | Total score | Corr | Sig |
|---|---|---|---|---|---|---|---|---|
| QLQ-ANL27_1<br>QLQ-ANL27_2 | 17 | 27 | 3 | 2.34<br>2.10 | .447<br>.566 | 234<br>210 | .487 | .081 |
| Pain_1<br>Pain_1 | 17 | 6 | 3 | 3.26<br>2.14 | 2.65<br>.684 | 326<br>214 | .015 | .040 |
| Bowels_1<br>Bowels_2 | 17 | 5 | 3 | 2.62<br>2.21 | .663<br>.778 | 262<br>221 | .357 | .929 |
| Urinary frequency_1<br>Urinary frequency_2 | 16 | 1 | 3 | 2.62<br>1.93 | 1.08<br>.928 | 262<br>193 | .569 | .011 |
| Clean more often_1<br>Clean more often_2 | 16 | 1 | 3 | 2.62<br>2.18 | 1.08<br>1.04 | 262<br>218 | .124 | .234 |
| Proximity toilet_1<br>Proximity toilet_2 | 16 | 1 | 3 | 262<br>1.93 | 1.087<br>.928 | 262<br>193 | .569 | .011 |
| Limb oedema_1<br>Limb oedema_2 | 16 | 1 | 3 | 1.18<br>1.25 | .543<br>.774 | 118<br>125 | .198 | .774 |
| Activities_1<br>Activities_2 | 17 | 1 | 3 | 2.41<br>2.17 | 1.12<br>1.10 | 241<br>217 | .387 | .387 |
| Sexual issues_1<br>Sexual issues_2 | 14 | 6 | 3 | 1.89<br>1.81 | .711<br>.520 | 189<br>181 | .786 | .511 |
| Erection_1<br>Erection_2 | 5 | 1 | 3 | 2.20<br>2.00 | 1.30<br>1.41 | 220<br>200 | .949 | .374 |
| Vaginal issues_1<br>Vaginal issues_2 | 8 | 3 | 3 | 2.41<br>2.12 | 1.13<br>.532 | 241<br>212 | .766 | .340 |

*Theme: physical/bowel-related*

*I have to run to the toilet for bowel movements.*

*Have to take 2 (antidiarrhoels) 20 minutes before I go out.*

*Too tired to do more than relax: pain disturbs rest.*

*Table 5. Significant bivariate Pearson correlations*

| Variable_1 | n | Variable_2 | n | Corr | Sig |
|---|---|---|---|---|---|
| **T1** | | | | | |
| QLQ-C30_1 | 19 | QLQ-ANL27_1 | 19 | .650[2] | p=.003 |
| QLQ-C30_1 | 19 | LOT-R_1 | 18 | -.563 | p=.015 |
| Cognitive function_1 | 19 | Role function_1 | 19 | .556[1] | p=.013 |
| Role function_1 | 19 | Social function_1 | 19 | .687[2] | p=.001 |
| Physical function_1 | 19 | Social function_1 | 19 | .610[2] | p=.006 |
| Emotional function_1 | 19 | Cognitive function_1 | 19 | .523[1] | p=.022 |
| QLQ-ANL27_1 | 19 | LOT-R_1 | 18 | -.525[1] | p=.025 |
| SexM_1 | 19 | SexF_1 | 19 | .952[2] | p=<.001 |
| **T2** | | | | | |
| SexM_2 | 14 | SexF_2 | 14 | .972[2] | p=<.001 |
| SexM_2 | 14 | Role function_2 | 14 | .580[1] | p=.030 |
| SexF_2 | 14 | Role function_2 | 14 | .630[1] | p=.016 |
| QLQ-ANL27_2 | 17 | Role function_2 | 17 | .590[1] | p=.013 |
| Emotional function_2 | 17 | Cognitive function_2 | 17 | .671[2] | p=.003 |
| SexM_2 | 14 | Social function_2 | 14 | .553[1] | p=.040 |

[1] Correlation significant at 0.05

[2] Correlation significant at 0.01 level

SexM/SexF=sexual issues according to gender

*Theme: sexual issues*

*No intercourse.*

*No sex – don't know if it would be painful.*

*The appointment timing can mean an 8 hour day (on the day of concurrent chemotherapy before radiation treatment).*

*I have not had sexual activity or used a dilator during treatment.*

*Patients' written comments 3 months post-treatment (T2)*

*Theme: physical*

*I'm somewhat limited in daily activities at work.*

*Had to cancel going to a concert: difficulty sitting and concentrating a little.*

*Problems leaving the house due to need to change stoma bag.*

*Theme: sexual issues*

*I needed encouragement to have sexual intercourse.*

*No pain on intercourse.*

## Patients' perceptions of information provision about managing side effects

The second aim of the study was to assess patients' perceptions of information provision about managing the side effects of the treatment during and following treatment. The EORTC QLQ-INFO25 showed no statistical differences for the total scale or the various items/subscales (Table 6). The overall

satisfaction with information provided as per the total scale was T1=3.31 and T2=3.12; (p=.270). Information about self-help was in the low range at both timepoints: T1=1.87 and T2=1.87 (p=.903), as was the dichotomous question about appropriateness of written information (T1=1.11; T2=1.17, p=.579). When feeling they needed less information, patients' scores were low (T1=1.93. T2=1.87; p=.580). When wanting more information, the scores were also in the low range (T1=1.76; T2=1.81; p=.579). There were high overall scores on the helpfulness of the information (T1=3.31; T2=3.12; p=.270) (Table 6).

*Patients' written comments at the end of treatment (T1)*

*Theme: information*

> *The information provided was too much to digest: just needed shortened versions.*
>
> *Would like more information into research into chemotherapy options for anal cancer.*
>
> *I was satisfied with the amount of information provided during treatment but not what happens after.*
>
> *Would like to have information on the outcome of treatment in between finishing treatment and PET scan.*

*Patients' written comments 3 months post-treatment (T2)*

*Theme: Information*

> *Much of the written information provided was irrelevant; information from the radiation oncologist was helpful. I went to MyAged Care myself for help.*
>
> *I received information on CD, tape and video and they all work. I can never say enough about the support and comfort I received from everyone. Thank you for making it all so easy.*
>
> *Information lacking regarding future treatments.*
>
> *I wish I had received more information once I had finished treatment. The burns and pain and then itchiness at home was never discussed how bad it would be.*
>
> *Would like more information on income protection.*
>
> *I wish I had received less information because all the pamphlets were overwhelming.*

### The influence of disposition on patients' perceptions of QOL

The final aim of the study was to consider the influence of patient perception of QOL. The LOT-R scales assessed disposition in levels of optimism or pessimism (Table 7). The summed scores showed no significant change at T2, although general optimism was reduced at 3 months post-treatment (T1: M=2.36: SD=.369; T2: M=.219, SD=.301, p=.067) (Table 8). The EORTC QLQ-C30_1 inversely correlated with the LOT-R_1 (-.563, p=.015) (Table 5).

*Theme: Emotional*

> *Initial meeting with (Dr) was very confronting and all about the 'bad things' that can/will happen – little focus on the positive side or good outcome. I was left devastated and not wanting to go ahead with treatment. Scary stuff.*
>
> *Strongly disagree with type of cancer being called 'anal' cancer, I feel that name is embarrassing; therefore, referred to cancer as bowel cancer to avoid stigma involved.*
>
> *Even rectal cancer would be less embarrassing to name.*

*Theme: Physical*

> *It's easy for me to relax if I'm in bed.*

## Discussion

This study assessed three issues considered important for patients undergoing chemoradiation for anal cancer. The first is QOL. The EORTC QLQ-C30 covers ten dimensions related to QOL – physical, role, social and emotional functioning, pain, fatigue, sleep, appetite, nausea, and bowel problems. This was a longitudinal study, timepoint 1 (T1) at the end of treatment when the acute reactions are likely to be greatest and timepoint 2 (T2) at 3 months following treatment, when treatment toxicities may be expected to have resolved. However, responses from the patients provided an insight into improvement and/or ongoing toxicity. On two single item global questions on the EORTC QLQ-C30 patients felt that their overall health and overall QOL had improved by 3 months post-treatment. Time and healing were positive factors in improving appetite, fatigue, appetite and pain around the anal opening on the EORTC QLQ-ANL27. However, anal cancer patients are a cohort where the effects of treatment continue at varying levels, often for their lifetime[31]. This may impact the person in every facet of their day-to-day life, especially when there is often an urgent need for a toilet. Sexual issues did not significantly change by T2, but the male cohort consisted of only five participants. The omission by many participants to complete questions on sexuality may indicate low importance or priority to the participants at this time when focusing on other side effects such as incontinence and discomfort.

The second issue reviewed is information. This study showed that the information provided to these patients had many inadequacies, especially the written information both during and following treatment, and this was verified by the patients' own written responses. There was no significant difference between timepoints for information provision or for overall satisfaction with information. This study found that many patients reported deficits in the information they wished to receive, especially about end-of-treatment issues, and what to expect. There was an overload of information for some patients during treatment and not enough specific information about what happens after treatment has been completed at 3 months.

*Table 6. EORTC QLQ-INFO25 scale*

| EORTC QLQ-INFO25 | n | Items | Item range | Mean | SD | Total score | Corr | Sig |
|---|---|---|---|---|---|---|---|---|
| Total questionnaire | 17 | 22 | 3 | 2.48<br>2.49 | .435<br>.557 | 248<br>249 | .537 | .932 |
| Information about illness | 16 | 5 | 3 | 2.23<br>2.21 | .698<br>.820 | 223<br>221 | .283 | .946 |
| Information about medical tests | 16 | 3 | 3 | 2.45<br>2.41 | .806<br>.661 | 245<br>241 | .382 | .843 |
| Information about treatments | 16 | 7 | 3 | 2.79<br>2.71 | .564<br>.546 | 279<br>271 | .586 | .546 |
| Information about other services | 17 | 5 | 3 | 2.16<br>2.18 | .745<br>.904 | 216<br>218 | .687 | .903 |
| Information about things you can do to help yourself get well | 17 | 1 | 3 | 1.87<br>1.87 | 1.02<br>1.02 | 187<br>187 | .705 | .903 |
| Written information | 17 | 1 | 3 | 1.11<br>1.17 | .332<br>.392 | 111<br>117 | .310 | .579 |
| Information on CD tape/video | 17 | 1 | 3 | 1.82<br>1.88 | .392<br>.332 | 182<br>188 | .310 | .579 |
| Satisfaction with the information received | 17 | 1 | 3 | 3.11<br>2.94 | .696<br>.826 | 311<br>294 | .230 | .455 |
| Wish to receive more information | 17 | 1 | 3 | 1.76<br>1.82 | .437<br>.392 | 176<br>182 | .471 | .579 |
| Wish you had received less information | 16 | 1 | 3 | 1.93<br>1.87 | .250<br>.341 | 193<br>187 | -.098 | .580 |
| Overall the information has been helpful | 16 | 1 | 3 | 3.31<br>3.12 | .602<br>.806 | 331<br>312 | .601 | .270 |

The third issue is disposition, which is an issue that may not often be considered in the clinical setting during radiation treatment. The awareness of the dispositional issues of the patients may lead to the framing of interventions to suit both pessimistic and optimistic patients for added efficacy, and may require different approaches to information provision and support. Johnson[32] tested the hypotheses that pessimists might benefit from concrete objective information based on self-regulation theory, and optimists might benefit from instruction in self-care and coping based on self-care theory. Her theory was supported in part when concrete objective information had a positive effect on mood among pessimistic patients, even during the most severe radiation therapy side effects[32]. Patients whose disposition level decreased following the treatment may provide a guide for health professionals to provide information in a more concrete and objective way.

*Table 7. Life Orientation Test – Revised (LOT-R) items*

| No | Items | 0–4 (strongly agree) |
|---|---|---|
| 1 | In uncertain times I usually expect the best | Scored |
| 2 | It's easy for me to relax | Filler |
| 3 | If something can go wrong for me it will | RS |
| 4 | I'm always optimistic about my future | Scored |
| 5 | I enjoy friends a lot | Filler |
| 6 | Its important for me to keep busy | Filler |
| 7 | I hardly ever expect things to go my way | RS |
| 8 | I don't get upset easily | Filler |
| 9 | I rarely count on good things happening to me | RS |
| 10 | Overall, I expect more good things to happen to me than bad | Scored |
| Filler: item not scored; RS: reverse-scored | | |

The number of participants available in the timeframe for this study reflects the relatively small numbers of patients being treated for anal cancer with the organ-preserving chemoradiation protocol. The sample size is similar to other studies researching this patient cohort[5,11,17]. It is worth noting that many similar published studies have generally used colorectal measures rather than the anal measure developed by Arraras et al.[16].

*Table 8. Life Orientation Test – Revised (LOT-R) scale*

| Scales | Items | Range | Mean | SD | Min | Max | Summed score | Sig |
|---|---|---|---|---|---|---|---|---|
| LOT-R_1 | 6 | 4 | 2.36 | .369 | 1.83 | 3.17 | 42.53 | |
| LOT-R_2 | 6 | 4 | 2.19 | .301 | 1.67 | 2.83 | 37.37 | .067 |

*Implications for nursing and the treating team*

The physical side effects of the treatment continued as reduced function due to acute and subacute pelvic and comfort issues. Importantly, for consideration of the treating team, is that many patients in this study felt uncertain about what was to happen at the end of treatment, and what would be happening in the early post-treatment phase. Patients may benefit from more tailored information about the early and later side effects and how to manage them, as well as the emotional effects. Nurses may need to consider implementing more frequent post-treatment supportive telephone calls or nursing reviews as part of standard practice.

Another supportive issues may be for managers to consider a multidisciplinary rehabilitative pathway post-treatment to support the patients through physical, functional, psychological and sexual issues to improve QOL issues[33]. Several issues may be outside the specific expertise and time commitment of the radiation oncologists who need to consider the medical surveillance of the patient following treatment. Multidisciplinary interventions, especially in the physical, psychological and sexual domains, may provide a more person-centred and individualised approach to patient care and support.

As a preparatory intervention, it may be useful to incorporate a dispositional measurement scale such as the LOT-R into screening of these patients before treatment begins. This scale only requires summing six responses for each patient to provide a score. This may help to provide more person-centred information for these patients.

Early identification and management of potentially distressing symptoms can assist with QOL issues and promote adherence to treatment; patient/family education may also minimise anxiety and promote self-care strategies[7,34]. In addition, improving discharge information outlining possible symptoms for the patient to be aware of may offer a level of reassurance. This study may provide some guidance to health professionals, both in radiation oncology and medical oncology, in preparing patients undergoing combined modality treatment for anal cancer. Furthermore, undertaking a qualitative study at longer timepoints may add rich data to our current body of knowledge in support of these patients.

*Limitations of the study*

The small number of participants in this study reduced statistical outcomes. There was a lack of a baseline survey of tumour symptoms before treatment commenced, and the 3 months post-treatment timeframe was too soon to be able to determine later, ongoing side effects. Many symptoms may persist for years and further research is needed to capture ongoing severity and prevalence as it affects QOL.

## Conclusion

Patients with anal cancer are a relatively rare cohort of cancer patients. Therefore, health professionals may have limited experience in understanding and managing the myriad of symptoms and side effects these patients experience pre-treatment, during treatment and on a longer-term basis as a result of their treatment protocol. Improved and ongoing end-of-treatment interventions by the multidisciplinary team may improve QOL for this patient cohort. Increased awareness may improve person-centred care for this relatively small cohort of patients.

## Conflict of interest

The authors declare no conflicts of interest.

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# Just a call away – supported self-management after treatment for early breast cancer: an evaluation of a new nurse-led telephone-based service in Central New Zealand

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**Keywords** early breast cancer, thriving after breast cancer, supported self-management, nurse-led telephone-based support

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## Abstract

**Introduction** Patients with low-risk early breast cancer have the lowest risk of recurrence in the first 5 years after treatment completion compared to other breast cancers. These patients would benefit most from an alternative supportive approach that maintains contact to access an individual's concerns and empowers people to return to a life after breast cancer.

**Objectives** To evaluate a new model of follow-up care by telephone with the nurse consultant.

**Methods** Twelve patients enrolled on the supported self-management service.

**Results** Patients preferred telephone-based follow-up, removing the need to travel to hospital. Nurse-led telephone-based follow-up provided continuity of care and instilled feelings of confidence, reducing worry about recurrence so patients could move forward after treatment for breast cancer.

**Conclusion** This new model of follow-up care with the nurse consultant has been well evaluated and is demonstrated to be a feasible and acceptable alternative to routine hospital-based follow-up.

## Background

### Follow-up and cancer survivorship

As a result of screening, early diagnosis, multidisciplinary working and better treatment, more patients are surviving breast cancer than ever before[1,2]. On completion of hospital-delivered modalities of treatment (surgery, chemotherapy and/or radiation therapy), patients are usually followed up for a variety of timeframes in outpatient clinics in conjunction with an annual surveillance mammogram and other recommended imaging.

Studies investigating traditional/conventional models of follow-up have identified that there are no advantages to these models in terms of surveillance of disease recurrence or in relation to psychological wellbeing[3–9]. Most recurrences are identified by patients themselves, and usually between routine appointments[8]. For low-risk breast cancer patients, the lifetime risk of local recurrence is 1% at year 1 increasing to 5% at years 3 and 4, indicating that intensive follow-up over 5 years adds little clinical value as few patients are likely to relapse within this timeframe[10,11].

An increase in breast cancer survivorship has led to a significant growth in the number of patients requiring ongoing breast cancer follow-up. Traditional models of follow-up are generally brief outpatient clinic appointments with a doctor that are disease-focused, intent on detecting disease recurrence and physical side effects rather than providing an individual and whānau-centred (family-centred) approach to their survivorship needs. However, treatment completion and moving forward can be an uncertain time for the individual and their whānau, who are often faced with a range of potential issues as a result of the breast cancer itself, side effects from treatments, fears about recurrence and uncertainty about the future[12].

As such, current traditional models of follow-up are not meeting the individuals' supportive care needs, nor increasing their ability to self-manage when transitioning from treatment for breast cancer to living well after treatment[13,14]. Subsequently, new models of post-treatment care have been developed and implemented, empowering the survivor and their whānau to manage their condition and move forward after treatment for

breast cancer[14–18]. Most programmes have focused on patients with low, and low to moderate risk of breast cancer recurrence, with the exception of the Royal Marsden NHS Foundation Trust Open Access Follow Up (OAFU)[19]. The Royal Marsden decided that all patients would be considered as potentially suitable for OAFU (including those at high risk of recurrence, BRCA carriers, and patients with mental health problems) as it was felt that the support and education OAFU offers would be beneficial. Irrespective of disease recurrence criteria, all programmes have employed a nurse-initiated and individual self-management approach to post-treatment care with rapid access to specialist medical care/clinics if new symptoms occur.

Nurse-led and self-management models of care have been found to have a greater capacity to respond to individual need, with individuals self-determining their own needs and empowering them towards self-management when transitioning from treatment to life after treatment[13–16,19–21]. Evaluation of the Royal Marsden OAFU found that a significant part of this service that was working well for women was the role of the breast nurse specialist whose professionalism and expertise was hugely valued, engendering trust and enabling women to open up[19]. Women viewed the breast nurse specialist as the lynchpin in helping them transition from end of treatment to follow-up, as they could direct their questions and concerns to someone with knowledge and take the pressure off their relatives. However, for some women in the evaluation of OAFU, it was cited that it would be useful if there was 'check in' by the OAFU breast nurse specialist at set points over the 5 years to see how they were going[19].

The majority of post-treatment programmes have embraced the use of nurse-led telephone-based support, healthcare delivery by telephone. This method has proven acceptable to patients, secondary and primary care health providers[14,21]. When comparing hospital outpatient follow-up versus telephone follow-up after treatment for breast cancer in one randomised equivalence trial, telephone contact was found to be well received by patients, with no physical or psychological disadvantage[16]. It was deemed suitable for patients at low to moderate risk of recurrence, for those travelling long distances or with mobility problems, and that the telephone nurse-led service decreased the burden on busy hospital clinics[16].

Cancer survivorship is now recognised nationally and internationally as a priority. Breast cancer is the most common cancer in New Zealand women, with approximately 3,500 new cases per year[2]. As treatment outcomes continue to improve, increasing numbers of breast cancer patients are entering follow-up, and consideration needs to be given to a new model of follow-up[21] that can better meet the needs of the individual and their whānau, and supports a self-management approach after treatment for early breast cancer.

## A new model of supported self-management care

### Key drivers

Key drivers for a new improved model of care were the number of patients requiring follow-up after treatment for low-risk early breast cancer or pre-invasive cancer, and the impact that this was having on the availability of appointments to see new patient referrals and patients with metastatic or locally recurrent disease. The lead CNS breast care did not have the capacity to provide additional nurse-led follow-up care for low-risk breast cancer and pre-invasive cancer patients due to the workload of new breast cancer patients and the complex care needs of high-risk and metastatic breast cancer patients.

The opportunity for people treated for early breast cancer to have access to follow-up support beyond the scope of traditional outpatient care at one regional hospital – the Palmerston North Hospital located within the MidCentral District Health Board (MDHB) in central New Zealand – arose by working in partnership with Breast Cancer Foundation New Zealand (BCFNZ), a non-government funded organisation. This was a new approach to working with other healthcare sectors, Palmerston North Hospital and BCFNZ working together to address the needs of patients living and moving forward after an early breast cancer diagnosis or pre-invasive cancer.

A nurse consultant (NC) (whose main responsibilities include expert practice, leadership, consultancy, education and practice and service development) employed by BCFNZ provided nurse-led telephone-based consultations with patients at set intervals as part of care shared between the lead breast care clinical nurse specialist (CNS) and the patients' clinical specialists'.

### Development of the new service

A person-centred partnership between Palmerston North Hospital and BCFNZ was established to develop a proactive, holistic, nurse-initiated telephone-based follow-up for low-risk breast cancer and pre-invasive cancer patients as an alternative to outpatient clinic visits. At the time of the partnership's inception, it was estimated that approximately 30 patients per year would potentially be eligible for this follow-up based on multidisciplinary meeting (MDM) data in 2017 and 2018.

The focus of this new follow-up service was to enable supported self-management that provides flexibility on the type and amount of input required, with the intent of freeing up outpatient clinic resources to deliver care to new or high-risk breast cancer patients. This new model of follow-up was launched at Palmerston North Hospital in September 2019 with the first enrolments in November 2019.

### Identification of suitable patients

Patients are identified as potentially suitable for referral to the supported self-management follow-up service at the MDHB Palmerston North Hospital breast cancer MDM at the time of their diagnosis. These patients are:

- All patients with a diagnosis of ductal carcinoma in-situ (DCIS) only who have undergone mastectomy or wide local excision with clear margins and adjuvant radiation therapy if required.
- Grade 1 or 2 T1N0M0 breast cancers who have undergone mastectomy; or wide local excision with clear margins and adjuvant radiation therapy; and who are not receiving adjuvant endocrine therapy.

### Referral process

All breast cancer patients identified as suitable for the supported self-management telephone service are seen in clinic by the lead breast care CNS at 6 months after surgery or radiation treatment completion. Prior to attending the appointment with the lead breast care CNS, each patient receives a patient information booklet outlining the aims of the supported self-management service and what it offers patients, and explains who to contact, and how, if patients have any concerns.

At the 6-month clinic appointment, in addition to addressing the healthcare and wellbeing needs of the patient and their whānau, the lead breast care CNS discusses the supported self-management telephone-based service with the patient and, if they are agreeable, obtains written informed consent from the patient for referral to this service. This consent clearly outlines that it includes permission for the BCFNZ NC to have access to the patient's clinical information. The lead breast care CNS generates a referral to the supported self-management telephone-based service after obtaining patient consent. The nurse also writes a letter to the patient's GP following this clinic appointment, making them aware of:

- The patient's referral to the supported self-management telephone-based service and what the service provides as an alternative to hospital-based follow-up appointments.
- Any prescriptions it is expected the GP provides/repeats related to the patient's breast cancer treatment and/or follow-up.
- The need for the GP to request an annual surveillance mammogram and specify the month the mammogram is due.
- How to achieve rapid access to a specialist clinic at MDHB if required.

It is important that patients remain under the clinical responsibility of their specialist at Palmerston North Hospital even if they are enrolled in the supported self-management telephone-based service.

### Assessment as part of the joint patient and nurse telephone consultation

The BCFNZ NC provides expert telephone consultation/check in with the patient at set intervals. These intervals are within 2 weeks of patient referral to the service, then at 3 months, 6 months and 6-monthly thereafter for up to 5 years.

Core components of the joint patient and nurse telephone consultation are – health and wellbeing, quality of life, self-management of symptoms, annual surveillance mammography, healthy lifestyle advice, and referral to counselling and physical rehabilitation (including lymphoedema services) and other specific services the patient may need (cultural, sexual and reproductive, relationship, work and education related, financial and spiritual).

The BCFNZ NC ensures rapid access back in to specialist care/clinics at Palmerston North Hospital if new symptoms occur that could represent recurrence of their breast cancer or if patients raise concerns that require them to see their specialist.

During the time the patient is under the care of the joint Palmerston North Hospital and BCFNZ nurse-led telephone-based service, any prescriptions are organised through the patient's GP. If there are issues with a patient accessing prescriptions for a breast cancer/treatment related issue, this will be discussed by the BCFNZ NC with the GP but, if necessary, with the lead breast care CNS to review if the patient's MDHB specialist can organise a prescription for the patient.

After each follow-up interaction with a patient, the BCFNZ NC generates a letter to the GP. This letter follows a pre-specified template including assessment of symptoms, review of general health and wellbeing, and confirmation that surveillance mammography is being undertaken. It also documents if any referrals to other services are generated.

At the end of the 5-year follow-up period, in liaison with the BCFNZ NC, the lead breast care CNS at Palmerston North Hospital will write to the patient's GP formally transferring the patient's care from the hospital to the GP. This letter will outline any specific issues the GP needs to be aware of and the requirement for ongoing surveillance mammograms.

An overview of the nurse-led telephone-based service is outlined in Figure 1.

## Method

### Study design

The study was designed as a postal survey, consisting of four sections: (A) basic demographics; (B) disease and treatment (year of diagnosis and how long since completing treatment); (C) information and support needs (what is deemed important to discuss); (D) the new service (expectations and satisfaction with the pilot service). The postal survey was anonymous and pre-paid envelopes for completed surveys were included.

### Data analysis

Quantitative data: descriptive statistics were used, including counts and percentages. Qualitative data: thematic analysis was used to identify themes within the data.


*Figure 1. An overview of the nurse-led telephone-based service*

### Participants

Participants were patients who have transitioned to the supported self-management telephone-based service in the first 12 months of the new service being implemented. Twelve patients had been enrolled since November 2019; 11 were invited to participate in the postal survey. The last patient to be enrolled on the service was in October 2020, and subsequently it was deemed too soon to include this patient in the evaluation. Postal surveys were sent to 11 patients in November 2020.

### Service development

As this was a service delivery project, ethics approval was not required. Participation in this survey evaluation was voluntary.

## Results

### Patient characteristics

Demographic characteristics for the sample are represented in Table 1. Six out of the 12 patients were diagnosed and treated for early breast cancer (invasive) and the remaining six patients were diagnosed and treated for ductal carcinoma in situ (DCIS).

### Surveys

Eight out of the 11 patient (73%) surveys were completed and returned. Seven patients identified as New Zealand European and one patient as Māori. Five of the eight respondents (62.5%) lived more than 10km from Palmerston Hospital, with one living between 5–10km from the hospital and two patients living within 5km.

At the time of the survey, patients were at different stages post-treatment (6 months – 1 year, 1–2 years, 2–3 years, and over 3 years). Irrespective of time since diagnosis and completion of treatment for breast cancer, patients retained a need for information and support.

### Information and support needs

Patients were asked to rate what they felt were important issues to discuss or review during their follow-up appointments with the NC. These were ranked on a scale of 1–10, with 1 being least important and 10 most important. The results, illustrated in Table 2, indicate that the most important issues to discuss for patients who responded to the survey were treatment side effects, how they were feeling, and self-care. Whilst the other topics of health and wellbeing, whānau concerns and managing work commitments also ranked highly amongst many respondents, some felt they were not important issues to discuss during follow-up.

An additional comment from one responder was the importance of providing information on other services available such as psychology services. This patient had undergone their surgery in the private sector and felt that they were having to work out a lot of things on their own.

The survey specifically asked what help the patients had received from the BCFNZ NC during their telehealth consultations. The answers are illustrated in Table 3 and indicate the NC was able to help respondents with information on their surveillance, who to contact for advice, and referral to a variety of supportive care services.

### Thematic analysis

Two main themes were identified, forming patient experience – convenience of telephone-based follow-up, and nurse-led support.

#### *Convenience of telephone-based follow-up*

Patients preferred telephone-based follow-up, removing the need to travel to hospital for face-to-face follow-up. Patients valued the convenience nurse-led telephone-based follow-up offered (a time and day convenient to the patient). This can be seen in the following comments:

> *Phone calls were more convenient than visits (this is really important to me). Having a health professional who understands what I'm going through and she is only a phone call away is fantastic.*
>
> *It was great to discuss without having to travel anywhere. It felt great to have that contact.*
>
> *The ease and immediacy of the support I received.*
>
> *Accessible healthcare which has enabled me to get on with my life.*

#### *Nurse-led support*

Nurse-led telephone-based follow-up provided continuity of care and instilled feelings of confidence, reducing worry about recurrence so patients could get on with their life. This can be seen in the following comments:

> *She was often the only person who made me feel okay how I was feeling and reassured me about how I felt when it seemed people weren't supporting me or being unreasonable.*

*Table 1. Demographic characteristics*

| Patient details | Number (n=12) |
|---|---|
| **Age** | |
| 40–49 | 3 |
| 50–59 | 4 |
| 60–69 | 3 |
| 70–79 | 1 |
| 80–89 | 1 |
| **Ethnicity** | |
| NZ Maori | 2 |
| New Zealand European | 7 |
| Other European | 3 |

*Table 2. Patient-ranked level of importance for information and support needs*

| Level of importance for information and support needs | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|
| Treatment side effects | | | | | | | | | 1 | 7 |
| Self-care | | | | | | | | | 2 | 6 |
| Health and wellbeing | | | | | 1 | | | 1 | 1 | 5 |
| Whānau/family concerns | | 1 | | | | 1 | | | 2 | 4 |
| How you are feeling | | | | | | | | | | 8 |
| Managing work and other commitments | | 1 | | | | | | | 3 | 4 |

*Table 3. Assistance received from the BCFNZ NC during the telehealth consultations*

| Did the breast care nurse help with: | Yes | No | N/A | Comment |
|---|---|---|---|---|
| Informing about annual mammogram and/or MRI | 7 | 1 | | One patient indicated they preferred face to face |
| Who to contact (BCFNZ nurse) if any new concerns or symptoms | 7 | 1 | | |
| Putting in touch with other support or allied services e.g. physiotherapy, Cancer Society etc. | 6 | 1 | 1 | Patient who said no stated it was not needed |
| Putting in touch with services to help with worries, fears or emotional issues | 6 | 1 | 1 | |

> *To have the confidence to say whatever you needed to without anxiety.*
>
> *I felt "looked after" to the extent that I stopped worrying about anything and was able to get on with other facets of my life.*
>
> *I really valued the breast care nurse's care. I think her follow-up would have been superior to a clinic appointment due to the lack of time restraint and the ease of access.*

Overall, seven out of the eight patients (88%) were completely satisfied with breast nurse follow-up care received by telephone. Only one patient reported feeling somewhat dissatisfied and prefering face-to-face clinician-led follow-up at the hospital.

At the end of the survey, patients were asked to provide recommendations for improvement. Patients' comments (below) demonstrated that they would like the nurse-led telephone follow-up service to continue. Patients would like this service to be offered from the start, from completion of treatment. This can be seen in the following comments:

> *Having this contact right from start would be wonderful. I hope that it is available now, right from breast operation onwards. As a private patient I felt very alone and I didn't know who to ask about anything to do with my pain.*
>
> *I sincerely hope this service continues. The only downside is I have never met [the nurse] in person.*
>
> *Perhaps a text a couple of days in advance of the call would assist – in order to prepare.*
>
> *I think the concept of this new service is great, I hope it continues. I'm sure others will benefit from the service.*

## Discussion

The supported self-management telephone follow-up service provided jointly by Palmerston North Hospital and BCFNZ was well received by patients. Most patients (88%) reported that they were completely satisfied with the nurse-led telephone-based service. Only one patient reported feeling somewhat dissatisfied and prefering face-to-face clinician-led follow-up at the hospital; this patient has returned to a hospital-based follow-up.

Notably, even though five out of the eight patients (63%) were 2–3 years out from treatment, patients retained a need for information and support with self-management long after completion of treatment. Patients' comments clearly showed a preference for telephone follow-up with the NC, as this removed the necessity to attend follow-up in hospital outpatient clinics. Patients who lived in remote rural areas or those with limited transport options particularly valued having a nurse-led telephone consultation.

Telephone consultations enabled patients to discuss their individual supportive care needs without time restraints, enhancing optimal self-management and wellbeing with support from the NC. The new telephone-based service also proved an important tool during the COVID-19 outbreak, maintaining contact and support whilst keeping patients and health providers safe.

Referral of patients has been slower than expected at Palmerston North Hospital. Following the launch of the programme it became apparent that the patient group who ideally should be referred to the telephone-based follow-up service were also being offered radiotherapy on the Fast-forward protocol and this requires that they are followed up in person at the hospital and outcomes are audited. Another study – EXPERT – has also led to lower than expected numbers being referred.

## Conclusion

This new model of follow-up care by telephone with the NC has been well evaluated and has demonstrated to be a feasible and acceptable alternative to routine hospital-based follow-up. This new model of survivorship has shifted from a predominant focus on detection of disease recurrence to wellbeing and reducing worry about recurrence, thus empowering the survivor and their whānau to manage their condition and move forward after treatment for breast cancer.

This new of model of follow-up has meet the needs of patients and their whānau (family) and as a result has been rolled out at Palmerston North Hospital. The scope of this shared follow-up model has been extended to include early breast cancer patients prescribed adjuvant endocrine therapy, maximising the opportunity to facilitate adherence to endocrine therapy and support patients with self-management of endocrine therapy side effects.

## Conflict of interest

The authors declare no conflicts of interest.

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Cancer Nurses Society of Australia

# Evaluating a culturally sensitive support group program for Arab–Australian people affected by cancer

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## Abstract

**Background** The diagnosis and treatment of cancer can cause significant psychological and physical distress for patients and their families. Participation in culturally appropriate cancer support groups has been reported to improve the psychological effects of cancer, including the patient's ability to cope with the illness. In Australia, culturally and linguistically diverse (CALD) communities, including Arabic-speaking people, face numerous challenges accessing and engaging in mainstream health support services.

**Objective** The purpose of this qualitative exploratory study was to describe the experiences of cancer patients, survivors, and their family members who participated in the activities of an Arabic cancer support group.

**Methods** Semi-structured, individual face-to-face interviews were conducted in the Arabic language using an interview guide. All interview data were transcribed verbatim in Arabic and thematically analysed.

**Results** Six participants agreed to participate in the interviews. Five key themes were identified – (1) a sense of belonging; (2) maintaining mental wellbeing; (3) empowerment through knowledge; (4) challenges in attending the group; and (5) envisioning support for the future.

**Implications for practice** Using culturally appropriate cancer support groups for Arab people affected by cancer is beneficial to improving their quality of life during the cancer journey.

## Background

Australia is a culturally diverse nation[1] and culturally and linguistically diverse (CALD) communities in Australia face additional challenges accessing and engaging in health services, often as a result of differing cultural practices, social isolation, language barriers, and poorer health literacy[2]. According to the 2016 Census, Arab immigrants comprised 3.2% of the population in Australia, and Arabic is the third most spoken language in the country[1].

Like any other population, the diagnosis and treatment of cancer for Arabic-speaking communities can cause significant psychological and physical distress[3]. However, the Arab–Australian community has unique cultural beliefs that can affect communication, coping strategies, and understanding of a cancer diagnosis[4,5]. Support groups are a common resource for people seeking information and support to help them cope with cancer.

Various benefits of cancer support groups have been reported. Firstly, cancer support groups can play a major role in identifying

the needs and gaps in clinical care which can lead to early assessment and intervention for the unmet needs in patients with cancer[6]. Furthermore, cancer support groups can address some of the information, and social and emotional needs, of cancer survivors which are not met by the existing health services[7,8]. There is evidence to support that attending a cancer support group improves the cancer survivors' ability to cope and communicate with other people and with health providers which in turn enables them to be more open about their disease. Finally, participation in a cancer support group allows cancer survivors to share their experiences with other cancer survivors in a safe, supportive environment as well as become role models for newer cancer survivors[9,10].

## Development of the support group for Arab cancer patients

Although there is strong evidence of the benefit of support groups for cancer survivors, there are limited culturally specific cancer support groups for Arab people in Australia.

The challenges for Arab cancer survivors are immense and include stigma and social misunderstanding of cancer treatment. With poorer outcomes and a high level of unmet needs for patients and survivors of cancer, culturally appropriate support groups specifically developed for Arabic-speaking people are crucial to ensuring that the needs of this population are met[4,5]. In response to the growing need, a cancer support group for Arabic-speaking people was formed in March 2009 at a large tertiary teaching and referral hospital in Sydney. This hospital is located in a region where Arabic is the fourth most common language spoken at home[11]. The aim of the cancer support group was to provide physical and psychological support for cancer patients, survivors, and their families, bridge the cultural gap, and reduce the strain on the public health system.

The cancer support group was led by an Arabic-speaking multicultural health worker and meetings were held monthly in an informal setting at the local hospital where participants (patients, survivors and family caregivers) could voice their concerns and socialise. The meetings were open to cancer patients, survivors and their family members, and all meetings were conducted in Arabic. Participants met monthly and each meeting lasted for approximately 90 minutes. Participants were given the opportunity to walk out anytime during the meeting if they felt tired or uncomfortable. For Arabic people, food is a powerful asset that binds people together and creates a sense of community. Therefore, at all meetings, various Arabic delicacies were provided to all participants.

The Arabic cancer support group focused on face-to-face information sessions to meet the Arab cancer survivors' preferences in receiving verbal information. The information provided related to living with a cancer diagnosis, healthy eating, exercise and stress management. Practical support included teaching relaxation techniques and mindfulness. Social activities included handcrafting, art therapy and leisure activities such as outings and picnics. Due to the diverse nature of the participants within the group in terms of subculture, religion and background, the group activities and sessions were designed carefully to cater to everyone's expectations whilst respecting their culture.

Funding to support the activities of the group was obtained from the multicultural health service and the first group meeting was held in March 2009. To the best of our knowledge, this is the only Arabic cancer support group in Sydney, Australia.

Anecdotal evidence indicates the benefits and positive outcomes of this support group on participants and their caregivers. However, to date, no formal evaluation of the group has been undertaken. Therefore, the aim of this qualitative exploratory study was to describe the experiences of cancer patients, survivors, and their family members who participated in the activities of the support group. The results of this study will guide future improvements to provide more tailored activities to meet the needs of the cancer survivors and their family members.

## Methods

### Research design

This study was undertaken using a descriptive qualitative research design[12]. The most frequently proposed rationale for the use of a descriptive approach to is to provide straightforward descriptions of the partcipants' experiences and perceptions[13]. This paper follows the consolidated criteria for reporting qualitative research (COREQ) 32-item checklist[14]. Ethical approval to conduct the study was obtained from the SESLHD Human Research Ethics Committee (ethics number 2019/ETH12567).

### Sampling and recruitment method

A convenience sampling method was used to recruit participants from an Arabic cancer support group. A short presentation about the study was provided during one of the support group meetings by two bilingual researchers who were not involved in the conduct of the support groups. All 15 support group members were invited to participate in the study and were provided with a participant information sheet; written consent was obtained prior to participating in the study. The inclusion criteria were: 1) aged 18 years and over; 2) had a diagnosis of cancer or was a cancer survivor or a family member; 3) attended the Arabic cancer support group for at least five sessions; and 4) were able to read and/or speak English or Arabic.

### Data collection and data analysis

Semi-structured interviews were considered the most appropriate method of data collection. A semi-structured interview guide was developed to explore and evaluate the impact of the support group on the Arabic cancer survivors' experience with cancer (Appendix A). Face-to-face interviews with the

participants were conducted in Arabic by researchers (IA and AA) who were fluent in both English and Arabic. Probing questions were used to elicit further explanations from the participants. All participants were interviewed individually in a private room at St George Hospital and the interviews ranged from 26–40 minutes. All interviews were audio-recorded and transcribed verbatim (Arabic). To maintain the participants' confidentiality and privacy, participants were given a pseudonym at the time of transcription.

The six-step inductive thematic approach as developed by Braun and Clarke (2006)[15] was used to analyse the data. Firstly, two researchers (IA & AA) immersed themselves in the data, checking the audio recordings and reading the transcripts to ensure the accuracy of the transcription process. The transcripts were then initially coded by two authors (IA & AA) and organised into potential themes. To ensure the themes remained consistent with the data, the transcripts were then re-read and the themes refined to produce higher-level concepts. Lastly, subthemes were developed that summarised the data. The themes, subthemes and the supporting quotes were translated to English via an external translation service. The English version of the themes and supporting quotes were checked by the co-authors (IA & AA) to ensure that the meaning was not lost in translation. The themes were revised and refined by the third author (HG) until consensus was reached among all authors.

### Participant characteristics

Of the 15 eligible participants, six participants (one male and five females) aged between 50–70 years were interviewed. Four participants were patients and two were carers. Participants had been attending the support group for a mean of 5 years.

## Results

Five key themes emerged from the qualitative data analysis: (1) a sense of belonging; (2) maintaining mental wellbeing; (3) empowerment through knowledge; (4) challenges in attending the group; and (5) envisioning support for the future.

### A sense of belonging

This theme explores the participants' sense of belonging that was created by being part of the support group. It comprised two subthemes – social connection and sense of community, and connected through a mutual cancer experience.

#### *Social connection and sense of community*

The members of the Arabic cancer support group mostly valued the social connection and sense of community the group provided them. Appreciation for the support received from other group members outside of the monthly group gatherings was expressed as feeling part of a community:

> *I do not feel that I am stranger between them and I feel that they are my brothers* [Hadeel].

Concerns over the welfare of other group members if they were going through a difficult time was highly valued and felt like a special bonding and connection:

> *The rest of the group here was always asking about us, and also members of the group came to visit us in the hospital* [Marial].

Meeting new people that members felt related to was also a benefit of belonging to the group:

> *I feel related to them, and I really feel that I want to be from this group... Plus, they are also people who are not very old, meaning they are almost around my age* [Victoria].

#### *Connected through a mutual cancer experience*

Sharing similarities and experiences of their cancer journey created a sense of connectedness for members of the Arabic cancer support group. Regardless of the members' types and stages of cancer, sharing their experiences enabled them to feel as if they were not alone in the journey. Sharing their mutual cancer experiences created a connection between the members of the group. Being able to have a conversation about their experiences, whether positive or negative, allowed a mutual understanding and opportunity to provide support for those going through more difficult circumstances and to also celebrate the positive milestones:

> *The group has a number of people, and each person has a problem that is different from the other, has a different way of thinking... and there is a conversation between them. This thing shows you that there are other people who have gone through experiences that may be more painful than the experience I went through* [Saba].

Most of the group felt that sharing experiences about treatments indicated to others at a similar stage in their cancer journey that the side effects or their emotions will not last forever. Additionally, sharing experiences may result in "forgetting your sadness" [Hadeel], encouraging others, and a sense of empowerment.

### Maintaining mental wellbeing

This theme explores how participating in the cancer support group was a method for maintaining participants' mental wellbeing. This theme comprises three subthemes – emotional support provides motivation, relaxation and psychological support activities, and rebuilding hope and a positive outlook.

#### *Emotional support provides motivation*

Motivation to attend the Arabic cancer support group was reported as having to ability to share their emotions while feeling valued and supported. Feeling emotional around the time of a cancer diagnosis, some members decided to attend as a way of expressing their emotions to others:

> *I found that my soul really began to relax, so I continued with her. I do not feel that I am stranger between them and I feel that they are my support* [Marial].

For some, motivation to attend the cancer support group was connecting with others because they lived away from family and friends, so they felt that they:

> *... had to go out of the house to meet people in the group and get to know them and talk to them* [George].

### *Relaxation and psychological support activities*

Members of the Arabic cancer support group indicated that activities that promoted their mental wellbeing and provided a method of relaxation were a positive component for the group:

> *... mindfulness and also many things that benefit the psychological state and have been very beneficial* [George].

Other group activities such as trips to the ocean were emphasised to create a sense of positivity for group members. Providing the opportunity to improve their psychological wellbeing was valuable and a motivator for continuing to attend the group:

> *One day, [group leader] took us to a place near the sea, and our mental status has changed greatly* [Marial].

### *Rebuilding hope and a positive outlook*

Cancer support groups provide members the opportunity to meet cancer survivors. People within the Arabic cancer support group reported that participating in the group provided them with a sense of hope. The optimism that the group generated provided other group members with a sense of relief that a cancer diagnosis does not indicate the end of their life, it is a way to rebuild their hope. Indeed, the group not only provides hope and positivity among those with a cancer diagnosis, it also benefits the carer/partner:

> *I was in need for someone to give me hope. The group gives hope and hope* [Noor].
>
> *It gave her relief that this disease does not mean the end* [George].

## Empowerment through knowledge

Members reported that their information needs were met through attending the support group. Learning about more than just their cancer diagnosis and treatment options was viewed as important for group members. Being provided with health information on topics such as nutrition and depression was beneficial for the group. Other sessions on general health information on diabetes and eye health were also held, including how to access these services. Empowerment through creating new knowledge was valuable for members of the cancer support group:

> *The other good thing is that [group leader] invites people to talk about different topics like eye problems and important advice for people with such problems* [Saba].
>
> *We were taking an hour on nutrition and an hour doing exercise and I really benefited from this course* [Noor].

## Challenges in attending the support group

This theme examines the challenges that the participants faced in attending the cancer support group and comprises two subthemes – difficult to access, and lack of funding.

### *Difficult to access*

Accessing the meeting place of the group was reported to be difficult for some members of the support group. The predominant access issue indicated by the support group was parking, particularly highlighting that free parking around the hospital is limited, making it challenging to attend the support group. Devon emphasised that:

> *A lot of times, most of the people who come here suffer from a parking problem. Sometimes I stand for more than half an hour to find a free spot* [Saba].

### *Lack of funding*

Despite the Arabic cancer support group providing benefits to the members, the lack of funding has substantially limited what activities can be provided. The members of the group are conscious that "... there is no support, there is no money" [Marial] and if they had to pay a fee to attend, then many would simply not be able to continue attending. Members reported that financial support would ensure the continued existence of this service within their community:

> *If attending the group need fees then we would have thought about, as you know there are transportation and many other things* [George].

Participants described the beneficial effects on their health and wellbeing of having funding to continue with activities, saying:

> *We used to go to the pool because she had a fund and my arm wasn't moving much, because they were taking the tumour from it. I started to move it and feel better after the pool* [Hadeel].

## Envisioning support for the future

This theme explores how participants see the future of the cancer support group and comprises two subthemes – a place to call our own, and diversity in activities.

### *A place to call our own*

Not having a specific meeting location and a place members could call their own was highlighted as a future aspiration of the group. Being within a busy hospital was expressed as not being an ideal location to ensure the longevity of the support group. As a result of the limited space, members believed that this may limit the growth of the group:

> *In the hospital it is crowded and hassle... there are many people* [Hadeel].

Having additional support to find a designated support group space would allow other members to join and have access to more resources:

*If the group were larger, meaning that there would be more people and a specific place for us, there would be more funding and more tools* [George].

*Diversity in activities*

Members of the Arabic cancer support group reported that more diversity in the topics and activities that were organised for the group would be valuable. Outdoor activities were highlighted as beneficial and something members would like to see increased in the future, particularly as they expressed it made a difference to their quality of life:

*I might suggest increasing the number of outdoor activities because they make a very big difference* [Marial].

In contrast, other members felt that they would like to see videos of cancer survivors describing how their lives have emerged and progressed after cancer. Providing a variety of activities and topics that will address the needs of the group members was seen as vital:

*Videos of people talking about their experience with the disease and how they triumphed over it... and how they became normal people... possible these videos will be presented here in the group* [George].

## Discussion

Culturally appropriate cancer support groups provide specific psychosocial support for people affected by cancer. The aim of this study was to report the development and experiences of participating in an Arab-specific cancer support group for cancer survivors and their carers. The findings of this qualitative study demonstrate that there are benefits and challenges to participation in a culturally sensitive cancer support group.

Given the extensive literature on the social benefits of the cancer support groups[10,16,17], it is not surprising to find that the results of this study indicated that the Arab cancer support group created a sense of community, alleviating the isolation and stigma while simultaneously promoting a strong feeling of belonging. Mutuality of experience led to a sense of belonging and cohesion within the group, which was a beneficial element of the group and is consistent with that reported in the literature[17]. Additionally, the cancer survivors also felt that the group helped them to reach out and ask for support, facilitating positive relationships and a sense of unconditional acceptance. Indeed, the cancer support group provided practical strategies to improve the physical and psychological health of the participants with a cancer diagnosis or cancer survivors by providing focused sessions to address the major issues they faced such as depression and nutrition. The support groups provided participants with information regarding their knowledge about cancer and coping strategies, which in turn created a sense of empowerment. The sense of control and increased knowledge about their cancer diagnosis and treatments participants reported in this study is similar to that reported in other literature[18].

The participants in this study, like any other cancer survivors, suffered from an immense level of anxiety involving fears of an ambiguous future, early death, and loss of control. However, their engagement and participation within the group gave them a sense of hope. The opportunity to share experiences with not only other cancer survivors, but cancer survivors from the same cultural background, assisted them to overcome the negative feelings associated with the diagnosis and provided a positive outlook. Furthermore, the support group activities were a motivator to attending the group as they gave meaning to their lives and assisted immensely with their mental wellbeing. People consider themselves healthy according to their ability to engage in activities that give dynamism to their lives, not just by the absence of disease[19]. Hence, the participants in this study demonstrated this very notion, as the opportunity to engage in activities such as beach day trips was valuable to their psychological health and in creating positivity. This result is similar to a previous qualitative study in which cancer patients reported that changes in routine and engagement in different activities (indoor and outdoor activities) are an essential reason to boost their mental wellbeing which in turn increases their treatment adherence[20].

Despite the benefits, participants reported some challenges in attending the cancer support group. One recurring barrier that arose in the group was the logistical factors such as finding parking or transportation[17]. The lack of funding was another challenge that restricted the number and type of activities that could be conducted for participants. Nevertheless, participants had several suggestions for improvements. One patient suggested that they should be giving free parking to attend these groups. Participants suggested that the government should support this kind of service which can make a crucial impact on cancer survivors and their family caregivers.

In this study, many participants did not want to attend a group run at the busy hospital, as perhaps this may be associated with a clinical environment and the negative emotions attached to cancer diagnosis and treatment, therefore heightening their anxiety. Effective support groups provide a range of activities to meet the diverse needs of individual members for information, socialisation, reduction of isolation and emotional support, and improved coping skills. As Ussher et al.[21] concluded about the ideal group:

*... whether the group provides a supportive environment, mutuality, and a sense of belonging, and whether it meets the perceived needs for community, unconditional acceptance, and information provision for the individuals attending.*

Arab people prefer verbal information rather than written information, even if written information was in the Arabic language. Oral communication was also the preferred mode of delivery of health information and support from healthcare professionals. This could be not only because of language barriers

but also because Arabs are more likely to trust information that is provided during face-to-face meetings between patients and healthcare professionals[22–25].

Being able to provide care in a patient's native language prioritises patient safety, promotes human connection, enhances efficiency, and decreases patient stress levels and health needs[26]. The English language can be a communication barrier as Arab people have a strong preference to receive health information in their native language. A quantitative study conducted by Butow et al.[27] with Arabic cancer survivors found that a greater proportion of participants reported having unmet needs compared to Anglo–Australians. Arab cancer survivors' unmet needs were primarily related to language and information. This finding highlights the need to involve bilingual health workers in health education and support to meet the needs of Arab cancer survivors and their families.

To the best of our knowledge, this Arab cancer support group is the first of its kind in Sydney, Australia. Evidence from this study supports the development of culturally appropriate cancer support groups to enable cancer patients, survivors and their family members to overcome the stigma of cancer, improve their knowledge, and have a better quality of life.

### Limitations

The study was undertaken at a single site and may influence the transferability of the results to other contexts. The sample size in this study was small, with only one male participating in the interviews, hence, the results cannot be extrapolated to other cancer survivors and carers. This limitation, however, was balanced by a rich description of the study process which provided depth across the research for those who may wish to replicate parts or all of the methods used. Further research involving larger sample sizes is needed to confirm the findings of this study.

### Implications

This study suggests several areas for potential interventions. Emphasis needs to be placed on raising awareness among Arabic cancer survivors and their families and physicians of the nature and potential benefits of cancer support groups. Some Arab cancer survivors find it difficult to talk to others about their experience with cancer. Thus, healthcare professionals should initiate discussions about joining the cancer support groups and informing Arabic cancer survivors about the available psychosocial services. Finally, we need to increase the number and access to culturally and linguistically appropriate cancer care and supportive services for Arab cancer survivors.

## Conclusion

This study has explored the impact of attending the cancer support group on the Arab cancer survivors' experiences with cancer. Our findings reinforce the benefit of attending the cancer support group and the impact of these groups on the patient's emotional, physical and social wellbeing and how they cope with cancer. This study also highlights the role of these groups in providing the Arabic cancer survivors with the information they need to meet their needs. Moreover, our findings highlight the impact of cancer support groups on Arab cancer survivors and their families in managing both their physical and emotional needs.

## Conflict of interest

The authors declare no conflicts of interest.

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## Appendix A

### Interview Guide and Data Collection Form

**Interview number:**_____ **Date Conducted:**_____

**Interviewer:**_____

**Interviewee Information:** *(If carer, loved ones type of cancer and diagnosis date)*

**Type of Cancer/s:**_____ **Date Diagnosed:**_____

**Gender:**_____ **Age:**_____

**Year joined support group:**_____ **Number of times attended:**_____

Reasons for attending and returning to the support group and what you enjoyed:

**I. Individual circumstances and needs**

***i) Tell me about your experience being diagnosed with cancer OR your experiences of your loved one being diagnosed with cancer***

Probe: 1. What were you most concerned about when you/they were diagnosed?

2. What did you need help with once you/they were diagnosed?

_____

_____

_____

_____

**II. Support group experience**

a. Getting involved

***i) How did you end up getting involved in the support group at St George Hospital?***

Probe: How did you hear about the support group?

***ii) Why did you decide to come to the support group when you did?***

***iii) About how many sessions have you attended OR how long have you participated in the support group?***

***iv) How long do you plan to participate in the support group?***

Probe: 1. What keeps you coming back to the support group?

2. What are the things that prevent you from attending the group?

3. How does attending the group interact with your other support networks?

_____

_____

_____

_____

b. Expectations of the group

***i) Before you got involved in the support group, what did you hope to learn or get from the group?***

Probe: When you joined the support group was there anything you experienced in the support that surprised you? If so, what was it?

***ii) In general, how would you describe your experience?***

Probe: 1. What is the best part of the support group?

2. What part of the support group would you change?

3. What do you get out of attending the support group?

c. Value obtained by the support group

***i) How have you benefited from participating in the support group?***

***ii) What do you gain from being part of the support group?***

Probe: 1. How did your experience with the support group affect your life?

2. What does the group mean for you?

**III. Opinion of the support group**

a. Developing the vision of the support group with participants

***i) In one sentence describe what the support group should stand for?***

Probe: What should the support group motto be?

IV. Feedback on the group

***i) If you had a suggestion or a comment about a support group session, how would you communicate it?***

Probe: 1. Would you feel comfortable to give feedback to the group leader?

2. Would you feel comfortable giving feedback through an anonymous comment box?

***ii) Is there any way in which you think the group can be improved?***

***iii) Is there anything else you want to share about the support group?***

Questionnaire adapted from:

Kith, Glenda. (2017). Developing A Peer Cancer Support Group Evaluation. Master's Projects and Capstones. 606. https://repository.usfca.edu/capstone/606