Australian Journal of Cancer Nursing

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The *AJCN* aims to provide a forum where debate and the exchange of views can take place. We welcome papers on contemporary professional policy or practice issues of concern and interest to cancer nurses.

Notes for contributors

All correspondence relating to the journal should be directed to the editors. Guidelines for contributors to the journal can also be obtained from the editors. The *AJCN* is published twice a year.

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Co-Editors

Professor Karen Strickland RN, PhD
Executive Dean
Edith Cowan University, School of Nursing and Midwifery
270 Joondalup Drive, Joondalup, WA 6027
Email k.strickland@ecu.edu.au

Associate Professor Jacqueline Bloomfield PhD, SFHEA
Director – Offshore Programs (Singapore)
Faculty Academic Lead Interprofessional Education
Susan Wakil School of Nursing and Midwifery, Sydney Nursing School
Faculty of Medicine and Health
The University of Sydney
Susan Wakil Health Building, The University of Sydney, NSW 2006
Email Jacqueline.bloomfield@sydney.edu.au

Editorial Board

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Senior Lecturer, School of Nursing and Midwifery Logan Campus,
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Nurse Practitioner Oncology/Haematology
South Eastern Private Hospital, 313–329 Princes Highway, Noble Park, VIC 3174

Diane Heart RN
Policy Officer
Australian College of Nursing, PO Box 219, Deakin West ACT 2600

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Editorial

Jacqueline Bloomfield • RN, PhD, MN, PGDip (Prof Healthcare Ed), PGDip (Midwifery), PGCert (Onc Nursing), BN
University of Sydney Susan Wakil School of Nursing and Midwifery, Faculty of Medicine and Health, The University of Sydney, NSW, Australia
Email jacqueline.bloomfield@sydney.edu.au

Karen Strickland • RN, PhD, MSc, PGCert, BSC, FHEA, FEANS
Professor of Nursing and Head of School, School of Nursing, Midwifery & Public Health, Building 10, Room 34, Faculty of Health, University of Canberra, ACT, Australia
Email karen.strickland@canberra.edu.au

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The last twelve months has been challenging for the Australian Journal of Cancer Nursing, with competing priorities and workforce issues reducing the number of manuscripts received and able to be peer-reviewed.

We know there is pressure on the membership and people are exhausted and experiencing high levels of anxiety in their roles due to lack of support structures, resource constraints and a complex healthcare system.

As a result of this, the CNSA Board of Directors, in consultation with the co-editors, has made a decision to review the purpose of the journal and focus on CNSA's remit to deliver and showcase nurse-led research that is easily accessible and digestible. Shifts in digital publishing combined with a changing profession means it's time for us to undertake a complete digital transformation strategy to ensure we are leading the way in this space.

Over the past three years, we have worked tirelessly to deliver content that we believe is relevant, thought-provoking and beneficial to the membership and it's now time for us to hand over to the Board of Directors so they can progress this review.

We would like to take the opportunity to say thank you to our readers, to our authors, to our peer reviewers and the editorial board for their contributions. Despite their busy lives, our peer reviewers volunteer their time for this important work, without which this journal would not be possible.

If you are interested in assisting CNSA with this review, or have any questions or concerns, please contact CNSA's Chief Executive Officer Jemma Still at jemma@cnsa.org.au.

To the editors before us – thank you for placing your trust in us and for your vision to create this important publication. We look forward to seeing and supporting the next iteration.

With thanks,

The editors,
Jacqueline Bloomfield and Karen Strickland

Australian Journal of Cancer Nursing

A gym-based exercise program for patients with breast cancer: a mixed methods evaluation

Meron Pitcher • MBBS
Head of Unit, General and Breast Surgery, Western Health, Footscray, VIC 3011, Australia

Julia White • BA, BArtsMgt, Grad Cert
Former Director, Western Health Foundation, Footscray, VIC 3011, Australia

Jarrod Borg • BExSci
Personal Trainer, EFM gyms, St Albans, VIC 3021, Australia

Darcie Vogan
Former Breast Care Nurse Administrative Manager, Western Health, St Albans, VIC 3021, Australia

Lisa Matar • RN
Breast Care Nurse Consultant, Western Health, St Albans, VIC 3021, Australia

Sue Komp • RN
Breast Care Nurse Consultant, Western Health, St Albans, VIC 3021, Australia

Sara Jorgensen • RN
Former Clinical Nurse Consultant Manager, Western Health, Footscray, VIC 3011, Australia

Sara Holton* • PhD
Senior Research Fellow, Deakin University, Institute for Health Transformation, Centre for Patient Quality and Safety – Western Health Partnership, Geelong, VIC 3220, Australia

**Corresponding author*

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Abstract

Objective To evaluate the acceptability, feasibility and perceived effectiveness of a gym-based exercise program from the perspectives of breast cancer patients and clinicians.

Methods Mixed-methods design (survey and interviews) to investigate patients' and clinicians' perceptions and experiences of a gym-based exercise program implemented at a public tertiary hospital in Melbourne, Australia.

Results Fifteen female breast cancer patients who had participated in the program completed a survey; eight female patients and four breast care clinicians participated in an interview. Participants thought the program was acceptable, assisted breast cancer patients to undertake regular and appropriate exercise, and improved health and fitness. Patients reported positive aspects including peer support, assistance with recovery, and improvements in mood. Most continued to exercise after program completion.

Conclusions Gym-based exercise programs appear to be an acceptable, feasible and potentially effective form of exercise for patients with breast cancer. Exercise should be included in breast cancer treatment plans.

Background

Breast cancer is the most commonly diagnosed cancer among women in Australia[1]. Breast cancer and its treatments can have a significant negative effect on a patient's physical and emotional health and wellbeing, and health-related quality of life (HRQL)[2,3]. There is increasing evidence that physical activity is an effective, well-tolerated, highly rewarding complementary behavioural intervention for enhancing quality of life as well as fitness among individuals with breast cancer[4–6]. In addition, regular exercise has been shown to have a positive impact on acute and chronic symptoms of breast cancer and reduce recurrence and mortality rates[3] as well as improving physical and mental health, weight management, fatigue and quality of life[7]. The Clinical Oncology Society of Australia has released a position statement recommending that exercise be part of standard cancer care practice and viewed as an adjunct therapy that helps to counteract the adverse effects of cancer and its treatment[8].

However, despite the physical and mental health benefits of exercise, many breast cancer patients do not engage in regular physical activity[9–13] and there is a need to increase opportunities for physical activity among breast cancer survivors[12]. It has been suggested that many exercise programs designed for patients with breast cancer do not meet their needs[10,14].

Further research is needed to identify the most acceptable, feasible and effective ways to provide exercise programs for patients with breast cancer. Little is known about breast cancer patients' acceptance, experiences and perspectives of gym-based exercise programs, including potential enablers and barriers to their use. Exercise programs are unlikely to be successful or used unless they meet the needs and expectations of the patients to whom they are offered.

The aim of this study was to evaluate a gym-based exercise program for patients with breast cancer from the perspectives and experiences of patients and breast care clinicians.

Methods

Study design

A concurrent mixed methods design (survey and interviews) was used to evaluate the acceptability, feasibility and perceived effectiveness of the gym program from the perspectives of breast cancer patients and clinicians. The use of different methods expands the breadth, depth and range of the research, resulting in more comprehensive results.

Setting and gym program

The study was conducted at Western Health, a large metropolitan public health service in the western suburbs of Melbourne, Australia. The health service provides care and treatment for a culturally and linguistically diverse population including a multidisciplinary breast service for over 150 women newly diagnosed with breast cancer (primary and metastases) each year.

One of the supportive programs offered to patients who receive breast cancer care at the health service is the EFM gym exercise program. This fully subsidised program provides patients at the end of their breast cancer treatment access to a supervised gym-based exercise program once a week for 12 weeks; since 2014 almost 130 patients have participated. Although each participant is provided with an individualised program of aerobic and resistance exercises, the program is offered in a group setting. The gym is located at a hospital in the health service where many participants would have received breast cancer treatment, and the program is facilitated by a qualified personal trainer and funded by the health service's charitable foundation.

Sample and recruitment

Survey and interviews (patients): Patients who had participated in the gym program (n=approximately 127) were invited to complete a survey and/or participate in an interview.

Interviews (clinicians): Breast cancer clinicians (surgeons, oncologists, breast cancer nurses, radiation oncologists and radiotherapy nurses) employed at the health service (n=approximately 23) were invited to participate in an interview.

Procedure

Survey and interviews (patients): Patients' names and contact details were sourced from the gym program participant list which is compiled and maintained by the breast cancer nurse consultant at the health service. Potential participants were sent an email invitation and a participant information and consent form. A follow up phone call a week after the email had been sent provided potential participants with the opportunity to ask questions about the study and indicate their intention to participate (in surveys and/or interviews) or not.

Interviews (clinicians): Breast cancer clinicians were invited to participate in the study via an email sent to their health service email address. The participant information and consent form was attached to the invitation email.

Interviews with both patients and clinicians were conducted by a member of the research team and an interview guide was used, informed by the researchers' clinical expertise, the published literature relating to breast cancer and exercise, and the research questions. The interviews were audio-recorded and transcribed for analysis. Interviews were conducted either via telephone or Zoom (online) at a time that was convenient for the participant. Interviews with patients were conducted between 19 October 2020 to 16 February 2021, and those with clinicians between 26 April 2021 to 17 May 2021.

Measures

Survey (patients): patients were invited to complete a self-administered anonymous online survey hosted on Qualtrics, an online software survey platform. The survey took approximately 15 minutes to complete and assessed respondents' perceptions of the acceptability, feasibility and effectiveness of the gym program. It consisted of five sections with mostly fixed-response questions:

1. Respondents' sociodemographic characteristics: age, relationship status, country of birth, language/s spoken at home, highest level of education and residential postcode, and breast cancer history (diagnosis and date, treatment).
2. Acceptability: perceptions and experiences of the program – nine items about reasons for joining the program, six items about concerns, and five items about experiences all rated using a five-point Likert scale ranging from 'strongly disagree' to 'strongly agree'.
3. Feasibility: perceived barriers and enablers to participation and continuation of exercise after the completion of the program and if so, the type of exercise undertaken.

4. Perceived effectiveness: four items about self-reported health-related quality of life, fitness levels and fatigue as a result of participating in the program, all rated using a five-point Likert scale ranging from 'strongly disagree' to 'strongly agree'.
5. Space was provided at the end of the survey for respondents to make free-text comments.

The survey was open from 11 October 2020 to 8 December 2020.

Interviews (patients): Interviews included questions about participants' reflections on the gym program, their experiences of the program, and perceived barriers and enablers to participation. Data were also sought about participants' sociodemographic characteristics (such as age, relationship status, country of birth, language/s spoken at home, highest level of education and residential postcode) and breast cancer history (diagnosis and date, treatment).

Interviews (clinicians): Clinicians' views were sought about: their perceptions and experiences of the programs; perceived barriers and enablers to women's participation in the program; clinicians' perceptions of the benefits and feasibility of exercise for breast cancer patients; whether they discuss exercise with their patients (and why/why not); their awareness of the gym program; and when and why they refer breast cancer patients to exercise programs (both internal and external to the health service). Data about participants' sociodemographic characteristics were also sought such as age, country of birth, and role and years employed at the health service.

The data sources for each aspect of the evaluation are summarised in Table 1.

Data management and analysis

The qualitative and quantitative data were collected concurrently but analysed separately. The results were considered together to address the study's objectives[15].

Descriptive statistics were used to describe and summarise all study variables. For analysis and in order to avoid low cell counts for smaller cohorts, responses to Likert-scale items were recoded to binary variables ('disagree' or 'strongly agree/agree').

Quantitative data analysis was conducted using IBM Statistics Version 26.

The interview transcripts and survey free-text comments were using content (conceptual) analysis[16]. The analysis was conducted by members of the research team and interpretations discussed within the research team until consensus was reached. Quotes have been used in the text to illustrate the findings (more extensive quotes are provided in Appendix 1).

Ethics approval and consent to participate

Completion and signing of the Participant Information and Consent Form or verbal consent provided at the beginning of the interview was taken as voluntary consent to participate in the interview component of the study (patients and clinicians). Completion of the survey was taken as implied consent to participate in the survey component of the study (patients). The project was approved by Western Health Low Risk Ethics Panel (QA2020.63_62183, 3 September 2020).

Results

Response

Approximately 127 patients have participated in the gym program. At the time of the study, seven patients had subsequently died. Email addresses were available for 63 patients. An email invitation was sent to the 63 patients and four emails 'bounced back'. Of the remaining 59 patients, surveys were completed by 15; a response rate of 25.4%.

Eight female patients and four clinicians completed an interview. Interviews were conducted via Zoom (n=6, 50.0%) and telephone (n=6, 50.0%). On average, the interviews with patients were 21.27 minutes in duration (range: 15.35–41.32 minutes), and the clinician interviews had an average duration of 11.96 minutes (range: 7.02–17.25 minutes).

Participant sociodemographic characteristics

All the survey respondents were women and on average aged in their mid-50s. Just over half were born in Australia; most had a post-secondary school qualification and were partnered. On average, the respondents were about 5 years post-diagnosis at the time of the study. All had had surgery as part of their

Table 1. Evaluation of data sources

Domain	Topic	Survey (patients)	Interview (patients)	Interview (clinicians)
Acceptability	Reasons for joining the program	✓		
	Concerns about joining the program	✓		
	Reasons for participating in the project	✓		
	Experiences of the program	✓	✓	✓
Feasibility	Continuation of exercise after the program	✓	✓	
	Barriers and enablers to participation	✓	✓	✓
Perceived effectiveness	Perceived effectiveness	✓	✓	✓

breast cancer treatment, and most had also had chemotherapy, radiotherapy or hormone treatment (Table 2).

Similarly, the patients who participated in an interview were on average aged in their mid-50s (range: 34–69 years) and half were born in Australia (n=4, 50.0%) and partnered (n=4, 50.0%). All participants were female. On average they were about 5 years post-diagnosis (range: 3–8 years) and most had had surgery (n=6, 75.0%); many had also had chemotherapy (n=5, 62.5%), radiotherapy (n=6, 75.0%) or hormone treatment (n=2, 25.0%).

On average, the clinicians who participated in an interview were aged in their late 40s (range: 38–55 years) and had been practising as a clinician for 20 years (range: 5–34 years). All were born in Australia – half were medical oncologists and the other half were breast care nurse consultants.

Acceptability of the program

Data were collected about participants' perceptions and experiences of the program.

Concerns about joining the program

A few survey respondents identified that they had concerns about joining the gym program including that they would not be able to do the exercises or the exercises would be too difficult, they would not be able to get time off work to attend the program, or they were concerned about the cost of attending the gym (e.g. for parking) (Table 3). The interview participants reported feeling hesitant to participate in the gym program initially as many had not participated in a group gym program previously.

Reasons for participating in the gym program

The participants reported both health and exercise program related reasons for participating in the gym program. The survey respondents reported that they perceived the benefits of the program to include reducing the risk of cancer recurrence and improving their health and fitness as well as wanting to exercise in a safe environment and a small group with exercises tailored to breast cancer and its treatment (Table 4).

Table 2. Survey respondents' sociodemographic and health characteristics

Characteristic	n (%)
Age (mean (range))	55.3 (34–70)
Born in Australia	8 (53.3%)
Speaks a language other than English at home	5 (33.3%)
Post-secondary school qualification	14 (93.3%)
Relationship status – partnered	12 (80.0%)
No. years since diagnosed with breast cancer (mean (range))	4.7 (3–9)
Breast cancer treatment	
Surgery	15 (100%)
Chemotherapy	8 (53.3%)
Radiotherapy	11 (73.3%)
Hormone treatment	9 (60.0%)

Experiences of the program

The survey respondents reported positive experiences of the gym program, including that the personal trainer was experienced and helpful and modified the exercises to meet their needs. They also indicated that the group environment was beneficial in providing them with a sense of support and community (Table 5).

Interview participants liked the gym facilities and said that although they first thought it felt like a "dungeon" it was actually a "small, cosy space" and a "very comfortable place" which felt "positive". The women appreciated that there were no mirrors at the gym, a trainer was always present, and a different exercise program was offered every session. They liked the gym instructors and felt that they were "lovely", "fantastic", "understanding", did a "great job" and accommodated their needs and limitations (e.g. caused by pain due to cancer treatment). Many participants stated that they had never been in a gym before they started the program and were not "usually a gym person" or "didn't think they would ever join a gym at their age"; they were therefore initially reluctant to participate at first. However, they "loved" the program and were "glad they took the risk and participated", and felt that it was "excellent" and a "god-send":

Table 3. Survey respondents' concerns about joining the gym program (strongly agree/agree)

I was concerned …	n (%)
That I would not be able to physically do the exercises (n=15)	4 (26.7%)
That I couldn't get time off work to attend the gym sessions (n=13)	3 (23.1%)
That the exercise(s) would be too hard for me (n=15)	3 (20.0%)
About the cost of attending the gym (e.g. parking) (n=15)	3 (20.0%)
That the time of the gym session made it difficult for me to attend (n=15)	2 (13.3%)
That I did not have appropriate gym clothes (n=15)	1 (6.7%)

Table 4. Survey respondents' reasons for joining the gym program (strongly agree/agree)

I was motivated to join the gym program because …	n (%)
I wanted to reduce the risk of cancer recurrence (n=15)	14 (93.3%)
I wanted to exercise in a fun and safe environment (n=15)	13 (86.7%)
The cost was reduced (n=15)	13 (86.7%)
I wanted to improve my health and fitness (n=15)	13 (86.7%)
I wanted to exercise in a smaller group (n=15)	12 (80.0%)
The exercise was tailored to breast cancer and its treatment (n=15)	12 (80.0%)
I wanted to meet other breast cancer survivors (n=13)	9 (69.2%)
My doctor encouraged me to join (n=11)	7 (63.6%)
My breast care nurse encouraged me to join (n=13)	8 (61.5%)

> *I wouldn't have gone to the gym, had it not been for this program* – Interview participant (patient).
>
> *I am not a gym person at all so going to a gym where you know people are out-competing each other and wearing beautiful clothes that's actually preventative … [but the gym was] a place I felt comfortable being* – Interview participant (patient).

They identified several benefits of the gym program including that it was free, offered at the hospital where they had received treatment, was only for women with breast cancer, and was a well-structured, individualised program.

Peer support

Many interview participants identified peer support as an important aspect of the program. They valued undertaking the gym program with other women who were "going through the same experience" which made them feel that "they weren't alone" and "more comfortable about joining the program", and they "didn't have to compete with healthy women". Participants reported that they particularly enjoyed the "camaraderie", support and friendship of the other women. One woman reported that she felt comfortable enough with the other women in her group to take off her wig while she was exercising. Many participants stated that their friendship with the other women had extended beyond the gym program, and they regularly met for social activities including lunch and coffee:

> *The group support provides a safety net where women can talk and console each other if need be. This is important once all the medical staff reduce their attention once surgery and treatments are over. It's a nice environment to relax and be around women who have similar [experiences]* – Survey respondent.
>
> *It was a great program and provided much needed social support (and exercise!) during treatment*– Survey respondent.

Clinician feedback

The clinicians who were interviewed thought the program was a "great initiative", especially given that the health service does not have a lot of resources. They also identified health benefits of exercise for patients with breast cancer, including reducing the risk of recurrence, assisting with weight management and fatigue, and increasing women's confidence. They believed it was important to regularly discuss exercise with their patients; however, felt the timing of such discussions depended on a patient's diagnosis and treatment. For example, for patients who do not require chemotherapy it would be appropriate to discuss the benefits of exercise at the first consultation, whereas for other patients who do have chemotherapy it would be better to wait until they have finished their treatment. One clinician commented "I can give them chemo and I can give them tablets. But what they need to do and probably the hardest thing is to exercise and optimise their BMI". Participants who were breast care nurses reported that they discuss exercise with patients when they first meet them as well as at the nurse-led survivorship clinic which is available for all patients and on their consultation checklist.

Table 5. Survey respondents' experiences of the gym program (strongly agree/agree)

I felt that …	n (%)
The personal trainer was experienced and helpful (n=15)	15 (100%)
The group environment provided me with a sense of support and community that was beneficial (n=15)	14 (93.3%)
I could complete all the set gym exercises (n=15)	13 (86.7%)
The personal trainer modified the exercises to meet my needs (n=15)	12 (80.0%)
Health service staff provided enough information about the gym program (n=15)	11 (73.3%)

Feasibility of the program

Many interview participants said that they would not have done any exercise during their treatment and recovery if it had not been for the gym program. Most survey respondents also reported that they had continued to exercise after completing the gym program, on average three to four times a week. The commonly reported types of exercise were walking and gym exercises (Table 6). Interview participants also reported that they had continued to exercise after the completion of the program, including continuing to attend the gym, undertaking other gym programs, playing tennis, and exercising and walking in their local parks (due to gym closures during the COVID-19 pandemic):

> *I have continued on with the program prior to the lockdown now at home I walk and exercise using programs from the internet* – Survey respondent.

Barriers and enablers to participation in the program

The participants (survey respondents and interview participants – patients and clinicians) identified several barriers and enablers to attending the program and consequently made several recommendations about improving access to the program. These included providing additional options for the location and days/times the program was available, improving affordability

Table 6. Continuation of exercise after the gym program

Continuation of exercise (type and amount)	n (%)
Have continued to exercise (n=15)	13 (86.7%)
Type of exercise	
Walking	9 (60.0%)
Running	1 (6.7%)
Cycling	2 (13.3%)
Gym	6 (40.0%)
Yoga	3 (20.0%)
Number of times per week	
3–4	8 (53.3%)
5–7	3 (20.0%)

of continuing with the program, and assisting women from culturally and linguistically diverse backgrounds to attend the program, given some may be concerned about not having sufficient English language skills to participate in the program or may have concerns about privacy as they may run into other members of their community there. It was also suggested that gym instructors ensure that exercises are suitable for patients with breast cancer. Other suggestions included enhancing the peer support aspects of the program (such as grouping women of similar ages, diagnoses and stages of treatment), making the program available to all patients with breast cancer, and offering women a tour of the gym and the opportunity to meet other women who were undertaking the program before they started a program to give them an overview of what it was like.

The interview participants believed that more women should be encouraged to do exercise and join gym programs such as this one. They felt that clinicians should "prescribe" exercise to their patients as part of their treatment plan. They thought information about exercise should be given to women once they had started their treatment for breast cancer as they tended to be too overwhelmed when they were first diagnosed (Appendix 2).

Perceived effectiveness of the program

All the survey respondents indicated that they felt their health and fitness and wellbeing and mood had improved after participating in the gym program (Table 7). Similarly, the interview participants (patients) identified many physical and mental health benefits of the program, including the positive impact the program had on their mood. They stated the exercise helped with their recovery from breast cancer, "improved their health outcomes", and was like an "anchor" as it was something that they could "control and helped to make [themselves] feel better" and was offered at "a time when needed". They thought that the program assisted with relaxation and weight management, helped them to cope with their diagnosis and treatment and to manage the side effects of their medication and treatment, and made them feel "better", "less irritable" and "good tired". One participant commented that as she "continued with the program she found her body was gaining strength and she was building muscles". Many participants stated that they were also motivated to participate in the gym program as they believed that exercise could help to reduce the recurrence of breast cancer. The clinicians who were interviewed also identified the benefits of regular aerobic and resistance exercise for patients with breast cancer, including decreasing the risk of recurrence, optimising weight management and enhancing general health and wellbeing:

> *I feel it's an invaluable program. I started to participate when I was undergoing chemotherapy and although it was tough at times persevering paid off. Exercise should be an integral part of cancer patients' treatment. There are so many ongoing benefits. It helps to reduce the symptoms of surgery and the drug treatments and also make you feel in control of your health and the recovery process*– Survey respondent.
>
> *I was anxious to do anything to stop my breast cancer returning*– Survey respondent.
>
> *I was still pretty fragile emotionally … [and] I actually [joined the gym program] to feel physically stronger*– Interview participant (patient).

Table 7. How survey respondents felt after completing the gym program (strongly agree/agree)

After completing the program …	n (%)
My health and fitness improved (n=15)	15 (100%)
My wellbeing and mood improved (n=15)	15 (100%)
I slept better (n=15)	12 (80.0%)
I felt less tired (n=15)	11 (73.3%)

Discussion

The aim of this study was to evaluate the acceptability, feasibility and perceived effectiveness of a gym-based exercise program for patients with breast cancer from the perspectives of patients and breast care clinicians. The findings suggest that the program is an acceptable, feasible and effective form of exercise for breast cancer patients, and – with some minor modifications to improve its availability, accessibility and affordability – should be continued, and exercise integrated into treatment plans for breast cancer patients.

Similar to participants in other studies[7,13], the women in this study reported that participation in the gym program had improved their health and wellbeing, and they described a range of psychosocial benefits. The breast cancer patients in this study and previous studies[12,13,17,18] have highlighted the influence of a range of factors related to the program's accessibility, affordability and availability as well as the program's instructors, on their satisfaction with the program. These include: the program's hours of operation, location and cost; the importance of having knowledgeable, empathetic, non-judgemental, approachable and enthusiastic staff; and opportunities to exercise with other breast cancer patients in a supportive environment.

One of the key benefits of the program identified by the participants of this study was the peer support provided by other women in the program. Previous investigations of exercise programs for breast cancer patients have also highlighted the importance of social support[12,13]. It has been reported that the opportunity to undertake physical activity with "similar others": increases women's enjoyment, confidence and motivation to exercise[10,13]; provides opportunities for social interaction and support which can decrease feelings of loneliness and isolation[17]; increases program adherence and reduces attrition rates[13,17]; and provides opportunities to develop ongoing friendships and interactions outside of the exercise program[13,17].

Strengths and limitations

This was a small study which recruited participants from one metropolitan health service. Accordingly, the participants' perspectives and experiences may not reflect those of breast cancer patients and clinicians in other settings. Only female breast cancer patients participated in this study and therefore, the findings may also not be generalisable to male patients or those with other types of cancer.

It was not possible to survey or interview patients who did not participate in the gym program. Future studies should include non-participants to understand if their needs and preferences are different to those of patients who do participate. The effectiveness of the program was assessed via participant self-reports of improvements to their health and wellbeing at one timepoint. It is recommended that future studies conduct pre- and post-analyses about the impact of exercise programs on breast cancer patients' health and fitness using validated psychometric instruments. Larger longitudinal studies would also provide important evidence about the long-terms effects of exercise on health and psychosocial outcomes for breast cancer patients.

The study was conducted during the COVID-19 pandemic (October 2020 – May 2021) and, due to infection control protocols at the study health service, patients and clinicians could only be invited to participate via email and the survey had to be completed online. It was not possible to accurately determine the number of patients and clinicians who received the invitation email; thus, the survey response rate is a conservative estimate based on the total number of patients for whom we had email addresses.

A strength of this study was the inclusion of both patients and clinicians. This enabled a wider investigation about the perceived benefits of exercise for patients with breast cancer as well as perceptions and experiences of the gym program.

Implications for health practice and policy

The findings of this study indicated several barriers to participation in gym-based exercise programs for patients with breast cancer. The design and implementation of future programs should take into consideration the program's availability, accessibility and affordability as these factors will be important for patients' adherence to the program and its success and sustainability. For example: providing options in terms of the location and days/times the program is available; offering low-cost memberships so patients can continue with the program; assisting patients from culturally and linguistically diverse backgrounds to attend; and enhancing the peer support aspects of the program, such as grouping patients of similar ages, diagnoses and stages of treatment.

Breast cancer clinicians can play an important role in the promotion of exercise and exercise programs for patients with breast cancer and should be involved in future exercise programs. Clinicians can raise patients' awareness of the benefits of exercise, encourage them to undertake regular and appropriate physical activity, and inform them about existing breast cancer specific exercise programs[13].

Conclusions

Supervised gym-based exercise programs such as the one evaluated in this study appear to be acceptable to breast cancer patients, have a positive impact on their self-reported health and wellbeing, and have psychosocial benefits including peer support.

Exercise programs provided in a safe and comfortable environment with supportive instructors can increase participants' confidence with exercise and provide a basis for future, regular and increased physical activity. The findings of this study indicate the potential benefits of integrating exercise into breast cancer treatment and care plans.

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Conflict of interest

The authors declare no conflicts of interest.

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Appendix 1. Survey respondents' free-text comments and interview participants' quotes

Participant comments

Perceived overall benefits of the gym initiative

Peer support

- *The group support provides a safety net where women can talk and console each other if need be. This is important once all the medical staff reduce their attention once surgery and treatments are over. It's a nice environment to relax and be around women who have similar [experiences]* – Survey respondent.
- *It was a great program and provided much needed social support (and exercise!) during treatment* – Survey respondent.
- *It was so good meeting other breast cancer patients and I would never have joined a gym without having taken part in the EFM gym program* – Survey respondent.
- *Our group of ladies have kept in touch and pre-COVID have met and enjoyed each other's company* – Survey respondent.
- *[I was motivated to join the program] because it was going to be only with either women who had been diagnosed with breast cancer or who were going through treatment… that was really big for me because, yeah, I just felt like I don't know if I'll be able to be like a young girl who goes to the gym* – Interview participant (patient).
- *[One of the motivators for women to join the gym program] is the chance to meet other people in a similar situation* – Interview participant (clinician).
- *The other great thing [about the program] is socialisation… it is great for the patients, and you know they make ongoing relationships and they just get their confidence back as well* – Interview participant (clinician).

Importance of exercise in recovery and minimising recurrence

- *I feel it's an invaluable program. I started to participate when I was undergoing chemotherapy and although it was tough at times persevering paid off. Exercise should be an integral part of cancer patients' treatment. There are so many ongoing benefits. It helps to reduce the symptoms of surgery and the drug treatments and also makes you feel in control of your health and the recovery process* – Survey respondent.
- *I was anxious to do anything to stop my breast cancer returning* – Survey respondent.
- *I can give them chemo and I can give them tablets. But what they need to do and probably the hardest thing is to exercise and optimise their BMI* – Interview participant (clinician).

Weight management

- *I had never attended a gym before as I was never interested. I saw a flyer at Western Health about the EFM program and I thought I'd try it as I had put on a lot of weight during chemo* – Survey respondent.

General health improvements

- *Eating and nutrition improved* – Survey respondent.
- *Physically stronger and a sense of moving forward after recovery* – Survey respondent.
- *I was still pretty fragile emotionally … [and] I actually [joined the gym program] to feel physically stronger* – Interview participant (patient).
- *I just, I feel like I felt stronger*– Interview participant (patient).

Participant comments cont…

Perceived benefits of the program

Valued aspects of the program

- *[I was motivated to join the program] because it was free* – Interview participant (patient).
- *The program was at the hospital where I've been going pretty much three or sometimes four times a week* – Interview participant (patient).
- *I wouldn't have gone to the gym, had it not been for this program* – Interview participant (patient).
- *[The trainer] actually gave me strength to just be confident that I can exercise* – Interview participant (patient).
- *I have children at school so the timing [of the gym program] was convenient for me* – Interview participant (patient).
- *I am not a gym person at all so going to a gym where you know people are out-competing each other and wearing beautiful clothes that's actually preventative … [but the gym was] a place I felt comfortable being* – Interview participant (patient).
- *[The trainer] was good fun … [and] really motivating* – Interview participant (patient).

Types of exercises

- *EFM gym program had a good variety of different exercises, many of which could be done at home which is a bonus as gym machines are not required* – Survey respondent.

Continuing with the program

- *I found it really hard to start with and I nearly gave up. But by the end of the 12 week program I loved it and had made friends. So I decided to continue and pay for the classes. I have been going for 5 years now* – Survey respondent.
- *It was a motivating experience. [name of instructor] was a supportive instructor who personalised the program for us. I have continued to attend because the gym now feels comfortable for me* – Survey respondent.
- *Familiar setting* – Survey respondent.
- *I didn't want to have to explain to a trainer my condition… it was important that instructor was familiar with the condition* – Survey respondent.

Concerns about the program

- *I was concerned that the trainer assumed I knew what to tell her about my medical issues that may result in problems with exercise* – Survey respondent.

Continuation of exercise after the program finished

Types of exercise

- *I have continued on with the program prior to the lockdown now at home I walk and exercise using programs from the internet* – Survey respondent.
- *Tai chi* – Survey respondent.
- *Tennis and continued with the EFM gym* – Survey respondent.

Appendix 2. Participant-identified barriers and enablers to attending the gym program

Participant comments

Improving access to the program / availability

Location

- *I think [the program] was wonderful, had it been closer to home I would have been happy to continue* – Survey respondent.
- *For some people transport [is a barrier to participating in the program) especially the older ones who don't want to inconvenience their family for more trips to the hospital* – Interview participant (clinician).
- *For some women I think the hospital environment [is a barrier to participating in the gym program], you know we do get some patients who just feel nauseous the second they walk in the hospital doors because of you know the association [with their breast cancer treatment]* – Interview participant (clinician).

Days/times

- *Timing: morning sessions would be good* – Survey respondent.
- *I think it was great and if I didn't need to go back to work full time I would have loved to continue* – Survey respondent.
- *Work was very generous… [taking time off to attend the gym program] wasn't a problem because I went over lunchtime… [but] if I was in a workplace that didn't do that, then that time would have been pretty difficult* – Interview participant (patient).
- *I think one of the barriers to the program is people who are working… a lot of patients who are working, they don't have flexible hours or they are not empowered at work, to be able to step out to go to an exercise program* – Interview participant (clinician).
- *For me, the only downfall is I guess that it's in the middle of the day … because people are still working and things like that. In the future it would be great to maybe offer one on a weekend or something like a boot camp for the weekend… Otherwise we're only getting a certain demographic of people who are retired or not working… motivation is hard enough without any excuse not to come* – Interview participant (clinician).

Affordability

- *Although we weren't charged for attending… it would be nice maybe for some ladies that we were offered an affordable program which will encourage the lady's to continue the program* – Survey respondent.
- *I think that the fact [the program] was free was critical because [the health service's patients] are generally… quite financially disadvantaged so getting them to pay for exercise was not something they could do* – Interview participant (clinician).
- *We highlight that [the program is free] to patients because a lot of people would say no if they can't afford it… and because it's free so they're not paying for it so they feel like they have to go because you know its wasting [the health service's] money* – Interview participant (clinician).

Accessibility

- *For some non-English speaking patients it's been confronting for them that they might go [to the gym] and not be well understood or not understand* – Interview participant (clinician).

Participant comments cont…

Ensuring the program/exercises are suitable for patients with breast cancer

- *I was unable to do some of the Yoga type exercises. Tailoring of exercises for women with osteoporosis* – Survey respondent.
- *If the trainer had more time to interview each participant, i.e. I didn't know a lot of the exercises would be bad for my pelvic floor and didn't know I should have told her I had a problem* – Survey respondent.
- *The exercise regime was too aggressive for my body; needed a more interval led approach to the exercise routine* – Survey respondent.
- *Well we all have had different surgeries & treatment… so yes as one young lady was still having chemo and not always feeling too well* – Survey respondent.

Enhancing peer support

- *Perhaps it would be good to group the women as to which stage they are at. I was ready to exercise and push myself… it was the right time and created a good motivating experience* – Survey respondent.
- *Try and group similar women… I probably started at a physically better state than [the other women in my group] and was younger and very conscious of them comparing themselves to me… I felt a bit uncomfortable… And so I think it would have been better had I if I were in a group of not necessarily younger women, but certainly women who are physically ready to [exercise]* – Interview participant (patient).

Further support

- *At times it would have been useful for a breast care nurse to attend to answer the questions some women had* – Survey respondent.

Australian Journal of Cancer Nursing

Rural versus urban cancer patients' receipt of patient-centred care: a cross sectional survey

Thembelihle Mathe* • RN, Bsc Nurs, Grad Cert (Crit. Care Nursing), MPH
Registered Nurse, Health Behaviour Research Collaborative, University of Newcastle, Callaghan, NSW 2308, Australia
Email thembelihle.mathe@uon.edu.au ORCID: 0000-0002-9104-7386

Alison Zucca • B Arts (Psyc)(Hons), MMsc, PhD
Senior Research Officer, Health Behaviour Research Collaborative, Health Behaviour Research Collaborative, University of Newcastle, Callaghan, NSW 2308, Australia ORCID: 0000-0003-0613-6307

Rob Sanson-Fisher • B Psyc, MClinPsyc, PhD
Distinguished Laureate Professor of Health Behaviour, Health Behaviour Research Collaborative, University of Newcastle, Callaghan, NSW 2308, Australia ORCID: 0000-0001-6022-2949

Breanne Hobden • B Psyc (Hons), PhD
Australian Rotary Health Research Fellow, Health Behaviour Research Collaborative, University of Newcastle, Callaghan, NSW 2308, Australia
ORCID: 0000-0002-8489-6152

Heidi Turon • B Psyc (Hons), PhD
Post-doctoral Researcher, Hunter New England Population Health, Booth Building, Longworth Avenue, Wallsend, NSW 2287, Australia
ORCID: 0000-0002-6386-3394

Lucy Leigh • B Math, B MRS (Radiation Therapy), PhD
Senior Statistician, Hunter Medical Research Institute, New Lambton Heights, NSW 2305, Australia ORCID: 0000-0002-5198-8843

Allison Boyes • B Arts (Psyc), MPH, PhD
Senior Research Fellow, Health Behaviour Research Collaborative, University of Newcastle, Callaghan, NSW 2308, Australia
Program Leader, Equity in Health and Wellbeing Research Program, Hunter Medical Research Institute, New Lambton Heights, NSW 2305, Australia ORCID: 0000-0003-1721-053

Corresponding author

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Abstract

ObjectiveTo investigate and compare the receipt of patient-centred care amongst rural and urban outpatients undergoing cancer treatment.

Methods Cross sectional survey of 444 (331 urban and 113 rural residing) adult cancer patients of heterogeneous cancer types receiving cancer treatment in four outpatient cancer clinics in New South Wales, Australia.

Results Patients received a mean of 15.70 out of 21 patient-centred care elements. Only 5% (n=21) of patients received all 21 patient-centred care elements. Information about actual treatment delivery and physical side effects were most frequently received (96%). Practical and psychosocial care were least frequently received (21–31%). Patients' rural or urban residential location was not significantly associated with the receipt of patient-centred care (p=0.963).

Conclusion Gaps in practical and psychosocial care occurred in both rural and urban cancer patients. Greater involvement of other healthcare professionals, such as general practitioners, could be considered to meet gaps in patient-centred cancer care.

Introduction

Cancer is a major cause of illness, accounting for 18% of the total disease burden and about 9% of the health system expenditure attributed to specific diseases in Australia[1]. Despite improvements in cancer survival globally, those living in rural areas generally experience disadvantages in relation to cancer care and have poorer outcomes compared to their urban counterparts[2–5]. With approximately a third of Australia's population residing in rural and regional areas, and higher cancer incidence and lower survival rates associated with increasing remoteness, it is imperative that high quality cancer care is delivered[1].

Healthcare challenges faced by rural cancer patients

Rural residents face challenges including: lower socioeconomic status; delayed cancer diagnosis; lower health literacy; lack of access to specialist healthcare services; higher rates of risky behaviour such as tobacco smoking and alcohol use; and environmental risks from farming or mining work[1,5–7]. Lower socioeconomic status often impacts treatment accessibility for rural cancer patients who may have less capacity to afford travel and accommodation[8,9]. Furthermore, less than 10% of the general medical workforce and cancer specialists are located rurally[10,11].

The lack of cancer treatment facilities in most rural areas means that patients may need to travel or relocate to access larger cancer centres for treatment, which can disrupt important social support networks, pose practical, personal and financial burdens[12], and may lead to psychological distress[9]. These burdens often occur in addition to the physical issues imposed by cancer treatment side effects including pain, sleep disturbance, nausea and fatigue[13]. On the other hand, rural patients being treated closer to home have less access to clinical and supportive cancer care services than those residing in urban areas[14]. Additionally, travel burden has been shown to influence the choice of treatment for breast and lung cancer patients living more than 100km from the nearest specialist hospital[6]. A systematic review highlighted that travel burden often negatively impacted cancer patients with regards to prognosis, appropriate treatment and quality of life[6]. Moreover, despite rural and urban cancer patients reporting similar information needs, inadequate practical support and information exchange relating to travel and accommodation resources between patients and healthcare providers may result in increased levels of anxiety and emotional issues for rural cancer patients which may not be of concern for urban patients[15].

Patient-centred care delivery

Patient-centred care is key in the delivery of quality healthcare and focuses on the provision of humane care that treats patients with dignity and respect[16,17]. According to the Institute of Medicine (IOM), patient-centred care is considered to be multi-dimensional[18] and involves cancer patients' perceptions of whether they receive best possible care aligning with their values, preferences and needs[19,20]. The dimensions of patient-centred care include physical comfort, emotional support, respect, communication and information provision, continuity and transition of care, care coordination, involvement of family and friends, and access to care[18,21]. Previous literature largely assessed patient-centred care in terms of patients' perceived satisfaction; however, patient-reported experience measures (PREMS) are considered optimal for measuring the patient-centredness of care delivery[22,23]. A patient-centred approach to healthcare delivery is associated with improvements in patient satisfaction, experiences of care, treatment adherence, and emotional health outcomes[18,24]. Health services may also benefit from patient-centred care through improvements in quality, safety and cost effectiveness of services[16,25].

The IOM and World Health Organization (WHO) have highlighted the need to identify and address gaps in the delivery of quality patient-centred care[17,18]. For example, across the cancer care trajectory, gaps in cancer care delivery reported by patients include not being asked about their preferred involvement in treatment-related decision making, despite wanting active involvement or a shared role in treatment decision making[19,26]. Monitoring for prevalent and treatable symptoms has also been less commonly elicited by cancer clinic staff, particularly for emotional symptoms including distress, anxiety and depression, compared to physical symptoms such as pain and fatigue[27].

While gaps in the provision of cancer care have been explored with samples of rural patients receiving treatment[10,28], fewer have included an urban comparison group[23,29], nor have studies comprehensively examined the delivery of patient-centred care. Examining discrepancies between optimal care and clinical practice can highlight gaps in care delivery[30]. Previous cancer patient experience measures are often limited by recall bias as patient care is assessed many months after the care has been delivered[31,32]. Also, previous measures assess satisfaction, rather than assessing concrete and actionable components of care[33]. Examining components of care recommended as reflective of best practice means that patients can more directly report on the services they received, rather than rating the quality of care received. Assessing cancer care delivery at the point of contact may help to minimise issues with recall. Consequently, we aimed to determine among patients receiving treatment for cancer, the extent to which patient-centred cancer care was received, and the differences in the reported cancer care receipt between rural and urban patients.

Methods

Design and setting

A quantitative cross sectional survey of cancer patients was conducted from October 2017 to March 2018. The study was conducted in four outpatient oncology clinics in NSW, Australia, located in metropolitan (n=3) and rural (n=1) areas. The four oncology clinics generally provide multidisciplinary care from clinicians including the treating oncologists, nurse practitioners, clinical nurse consultants, and specialist cancer nurses (such as breast cancer nurses). Access to other members of the allied healthcare team, including social worker, dietitian and physiotherapist, is provided as needed.

Participants

Eligible patients were presenting for an outpatient appointment at one of the participating clinics, were aged 18 years and above, were able to read English sufficiently to complete a survey, had a confirmed diagnosis of cancer, and were physically and emotionally able to complete the survey. Patients who were deemed by the oncology clinic staff as being too ill or distressed were not eligible to participate.

Procedure

Each day, clinical staff consulted their clinic lists and noted if any outpatients were eligible. Next, outpatients were approached by a trained research assistant in the clinic waiting rooms prior to their appointment, or within day treatment centres, and were provided with written information and a verbal explanation of the study. The research assistant was not involved in the provision of care within the clinic. The research assistant confirmed eligibility with the patient and invited patients to take part in the study. Patients who provided verbal consent to participate were given a touch screen computer tablet and instructions on how to complete the survey.

Participants completed the System for Patient Assessment of Cancer Experiences (SPACE) survey[34]. The modular survey assesses cancer experiences across each phase of the cancer care trajectory, from attending the clinic for the first time to follow-up care[30,35]. Participants completed the module related to their current phase in the cancer care trajectory. Although participants could complete the SPACE survey at every clinic attendance, they could complete each module once only. All participants who indicated that they were attending the clinic to receive cancer treatment or a mid-treatment review were invited to complete the treatment module of the survey. This study analysed participants' (n=444) responses to the patient-centred care survey items in the treatment module.

Measures

Cancer care experience

Patients' cancer care experiences were assessed by the SPACE survey which is a patient self-report tool measuring receipt of patient-centred care[34]. The SPACE survey was developed from a review of the literature, supportive and psychosocial care guidelines, and draws on existing surveys assessing patient satisfaction[36–40] and patient experiences[41]. Cancer care delivery was mapped to phases across the cancer care trajectory[34] and to key domains of patient-centred care as defined by the IOM[18] and Picker Institute[21]. The sample of patients reported in this study is part of the SPACE survey pilot sample. As previously reported[34], the survey was completed by 911 individuals on 1,056 occasions. This sample of outpatients attending Australian oncology treatment centres established acceptability and feasibility[34]. The SPACE survey was designed specifically for cancer patients in the Australian context and enabled the examination of care received by patients that is reflective of best practice pathways of patient-centred care. It is also tailored to the participants' phase of treatment to minimise recall bias[34].

Patient-centred care items relating to physical needs, psychosocial needs, navigating the system, treatment decision making, patient-centred communication and interaction style were assessed by 18 items with the response options: 'Yes, and I wanted this'; 'Yes, but I didn't want this'; 'No, but I wanted this'; and 'No, but I didn't want this'. Items relating to access to care, shared care and continuity of care were assessed by three items with the response options: 'Never'; 'Sometimes'; 'Mostly'; 'Always'; and 'Not applicable' (Table 1).

Patient demographic and cancer-related characteristics

Six survey items assessed age, gender, country of birth, highest level of education, home postcode and site of outpatient appointment. Three survey items assessed cancer type, cancer stage at diagnosis and time since cancer diagnosis.

Statistical analysis

Statistical analyses were conducted using STATA IC/16.1 (StataCorp, Texas, USA). Descriptive statistics were used to summarise the sample characteristics. A multiple linear regression was used to examine whether higher levels of patient-centred care were associated with rural or urban residential location whilst controlling for potential associated variables identified a priori via a review of the literature. The multivariable model adjusted for the following confounders: age; gender; country of birth; level of education; treatment centre site; type of cancer; stage of cancer; and time since cancer diagnosis. Standard assumptions for linearity were assumed (linearity, normality, homoscedasticity and independence of observations). These assumptions were checked and found to be satisfactory. Some missing data were largely due to an administrative error in the early stages of the survey and these data were assumed to be missing completely at random. Consistent with standard practice[42,43], if a participant had less than five missing values (n=147; 23%) of the 21 elements of patient-centred care, these values were imputed using the average of the non-missing values for that individual before creating the score. Participants (n=14) with six or more missing values could not be reasonably imputed and were excluded, leaving a sample of n=430 for the regression analysis.

Following the mean imputation on the original scale, the 4-point scale items were dichotomised to 'Yes' ('Yes, and I wanted this' and 'Yes, but I didn't want this') and 'No' ('No, and I wanted this' and 'No, but I didn't want this') as we were primarily interested in the care each patient reported as receiving. The 5-point scale items were dichotomised to 'Yes' ('Sometimes', 'Mostly' and 'Always'), and 'No' ('Never' and 'Not applicable'). For this sample, the 'Not applicable' response option reflected that the care items – had access to up-to-date information about treatment and test results, organised appointments at suitable times, and kept GP up to date – were not received as all patients in this sample were in the mid-treatment cycle and therefore these care items were relevant. This response scale may have been suited to the earlier phases of care from the first appointment at the clinic and diagnosis to early treatment.

The frequencies and percentages were calculated for 'Yes' (received care) or 'No' (did not receive care). An overall composite outcome score ranging from 0–21 examining overall receipt of patient-centred care was calculated, with a higher score representing a higher level of patient-centred care received. Scores were calculated only for those with complete data for all 21 elements of care.

The Accessibility or Remoteness Index of Australia plus (ARIA+) endorsed by the Australian Bureau of Statistics based on distance measures to the nearest service centres[44], was used to categorise patients' residential postcodes into rural and urban. Using the ARIA+ five categories, all inner regional, outer regional, remote and very remote patients' postcodes in our study were classified as 'rural', and all major cities were classified as 'urban'[45]. The same principle was applied to the categorisation of the treatment centres.

A p value less than 0.05 in the adjusted model was considered statistically significant. Possible collinearity between the outcome of interest (residential location) and the predictor variable (treatment centre site) was investigated as collinearity could reduce the precision of the regression model. To do this, a linear regression was performed with and without the treatment centre site and the variance inflation factor (VIF) scores were generated. The interactions between treatment centre site and residential location were also tested for potential confounding.

Ethics statement

Ethics approval was obtained from the Local Health District Human Research Ethics Committee.

Results

Participants

The SPACE survey could be completed by patients each time they attended the treatment centre. Some patients were therefore approached on more than one occasion and completed multiple modules of the survey. During the study period, a total of 985

Table 1. 21 item SPACE survey 'active treatment' module assessing patient-centred care

Survey question / item	**Response scale** *(only one option allowed)*
At your last appointment did any staff member ask whether you were experiencing any:	1. Yes, and I wanted this 2. Yes, but I didn't want this 3. No, but I wanted this 4. No, but I didn't want this
Pain?	
Fatigue?	
Side effects from the cancer or treatment?	
Distress, worry or sadness?	
Throughout your cancer care so far, did any staff members ask whether you were experiencing any:	
Problems with doing everyday tasks?	
Concerns about work issues?	
Concerns about money/financial issues?	
Concerns about legal matters?	
Concerns about how your family is coping?	
Since commencing cancer treatment, has a staff member asked:	
If you wanted to talk to people who have been or are going through a similar cancer experience?	
Since commencing treatment, have you received information about:	
Who the health professionals are that make up your treatment team?	
The role of each health professional in your care?	
Which member of your treatment team you should contact if you have specific questions or concerns?	
The purpose of any appointments related to your cancer care?	
Since commencing treatment, have you received information about:	1. Yes, and I wanted this 2. Yes, but I didn't want this 3. No, but I wanted this 4. No, but I didn't want this
Who to contact if you have concerns about any symptoms or side effects?	
What symptoms or side effects to watch out for?	
Which symptoms/side effects mean you should seek medical care urgently?	
What you can do to stay as well as possible while having treatment?	
Since commencing treatment, has your healthcare team:	1. Never 2. Sometimes 3. Mostly 4. Always 5. Not applicable
Had access to up to date information about your treatments and test results?	
Made an effort to organise appointments at times that suit you?	
Talked with or written to your GP so that they are kept up to date about your treatment (including test results and any side effects)?	

eligible patients were approached on 1,379 occasions. Patients completed the survey on 1,143 occasions (83% occasion response rate). Of the 985 patients who completed at least one module of the SPACE survey, 454 patients completed the module relating to the cancer treatment phase and are reported in this manuscript. From this sample, 10 participants were excluded due to a missing residential postcode, leaving a total of 444 participants included in the analysis. Participant- and cancer-related characteristics are summarised in Table 2, by rural and urban residential location.

Proportion of cancer patients who received patient-centred care

From a possible score range of 0 (did not receive patient-centred care) to 21 (received high levels of patient-centred care), only 5% (n=21) of participants received all 21 elements of care. However, as shown in Figure 1, the majority of participants received high levels of patient-centred care, with a mean of 15.70 (SD 3.75).

Which elements of patient-centred care were MOST received by cancer patients?

There were 12 patient-centred care elements reported to have been received by more than 80% of patients (Table 3). Patient-centred care most received focused on: who to contact about symptoms or side effects (96%); which symptoms or side effects to watch out for (96%); and which signs or symptoms to seek urgent medical care for (96%).

Which elements of patient-centred care were LEAST received by cancer patients?

There were five patient-centred care elements reported to have been received by less than 50% of participants (Table 3). Patient-centred care least received focused on: being asked about concerns regarding legal matters (20.9%); being asked about wanting to talk to people who have been or are going through a similar experience (25.2%); and being asked about concerns regarding money or financial issues (31%).

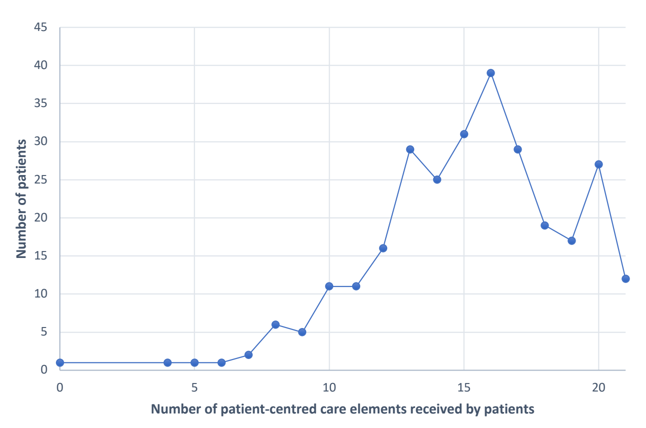

Figure 1. Overall receipt of patient-centred care

Table 2. Participant sociodemographic characteristics

Characteristic / category	Patient residential location n (%)		Total n (%) (n=444)
	Urban (n=331)	Rural (n=113)	
Gender			
Female	165 (49.9%)	63 (55.8%)	229 (51.6%)
Male	166 (50.1%)	50 (44.2%)	215 (48.4%)
Age group (years)			
18–54	75 (22.7%)	25 (22.1%)	100 (22.5%)
55–64	71 (21.5%)	25 (22.1%)	96 (21.6%)
65–74	106 (32 %)	39 (34.5%)	145 (32.7%)
75+	79 (23.9%)	24 (21.2%)	103 (23.2%)
Cancer type			
Haematological	87 (26.6%)	16 (14.3%)	103 (24.5%)
Bowel	46 (14%)	24 (21.4%)	70 (16%)
Breast	51 (15.6%)	14 (12.5%)	65 (14.8%)
Lung	37 (11.3%)	13 (11.6%)	59 (11.4%)
Skin	29 (8.9%)	14 (12.5%)	43 (9.8%)
Upper gastro-intestinal	27 (8.3%)	9 (8%)	36 (8.2%)
Urogenital	18 (5.5%)	11 (9.8%)	29 (6.6%)
Other	12 (3.7%)	3 (2.7%)	15 (3.4%)
Gynaecological	10 (3.1%)	4 (3.6%)	14 (3.2%
Brain	7 (2%)	1 (0.9%)	8 (1.8%)
Head and neck	3 (0.9%)	3 (2.7%)	6 (1.4%)
Time since diagnosis			
0–3 months	57 (17.4%)	12 (10.8%)	69 (15.8%)
4–6 months	56 (17%)	22 (19.8%)	78 (17.8%)
7–12 months	42 (12.8%)	24 (21.6%)	66 (15%)
More than 12 months	172 (52.6%)	53 (47.8%)	225 (51.4%)
Cancer stage at diagnosis			
Early	129 (39.5%)	46 (41.8%)	175 (40%)
Advanced and/or incurable	150 (45.9%)	44 (40%)	194 (44.4%)
Don't know	48 (14.7%)	20 (18.2%)	68 (15.6%)
Country of birth			
Australia	276 (84.4%)	95 (84.2%)	371 (84.2%)
Other	51 (15.6%)	17 (15.2%)	68 (15.5%)
Highest level of education			
High school or less	170 (52.2%)	52 (46.8%)	222 (50.8%)
Trade or vocational training	96 (29.5%)	47 (42.3%)	143 (32.7%)
University	66 (18.4%)	12 (10.8%)	72 (16.5%)
Treatment centre site			
1 (Urban)	180 (53.4%)	82 (72.6%)	262 (59%)
2 (Urban)	111 (33.5%)	2 (1.8%)	113 (25%)
3 (Rural)	0	13 (11.5%)	13 (2.93%)
4 (Urban)	40 (12%)	16 (14.2%)	56 (12.6%)

Note: Totals may not add to 444 due to missing values

Table 3. No. patients who received treatment-related patient-centred care ('Yes' responses) by rural and urban location (n=444)

Item	Urban n (%) n=331	Rural n (%) n=113	Total n (%) n=444
1. Informed about which signs or symptoms to seek urgent medical care for	314 (96%)	110 (97%)	424 (96%)
2. Informed about what sort of symptoms or side effects to watch out for	316 (96%)	104 (96%)	425 (96%)
3. Informed about who to contact about symptoms or side effects	319 (97%)	106 (94%)	425 (96%)
4. The healthcare team had up to date information about treatment received and previous test results	315 (96%)	102 (91%)	417 (95%)
5. The treatment centre organised appointments at suitable times	311 (95%)	103 (91%)	414 (94%)
6. Informed about what to do to stay well during treatment	307 (94%)	108 (96%)	415 (94%)
7. Informed about who to contact for specific questions or concerns	297 (91%)	100 (89%)	397 (90.6%)
8. Informed about the purpose of any appointments regarding cancer care	293 (90%)	101 (89%)	394 (90%)
9. Asked about side effects from the cancer or treatment	287 (87.8%)	95 (84.1%)	382 (86.8%)
10. Informed about who the health professionals are that make up the treatment team	283 (86.8%)	95 (84.8%)	378 (86.3%)
11. Asked about pain	281 (86.7%)	94 (84.7%)	375 (86.2%)
12. Informed about the role of each health professional involved in care	279 (86%)	88 (78.6%)	367 (84%)
13. Asked about fatigue	255 (79.2%)	88 (79.3%)	343 (79.2%)
14. Talked to the patient's GP about cancer care	218 (67%)	82 (75%)	300 (69%)
15. Asked about any distress, worry or sadness	74 (66%)	196 (61%)	270 (62%)
16. Asked about problems in doing everyday tasks	173 (52.6%)	61 (54.5%)	234 (53%)
17. Asked about concerns regarding how the family is coping	105 (46%)	40 (50%)	154 (47%)
18. Asked about concerns regarding work issues	69 (30.4%)	28 (34.6%)	97 (31.5%)
19. Asked about concerns regarding money or financial issues	67 (29.4%)	22 (27.5%)	104 (31%)
20. Asked about interest in talking to people who have been or are going through a similar experience	57 (24.4%)	23 (27.7%)	80 (25.2%)
21. Asked about concerns regarding legal matters	50 (22%)	14 (17.5%)	64 (20.9%)

Note: Totals may not add to 444 due to missing values

Rural versus urban residents' receipt of cancer care

As shown in Table 4, after adjusting the model for confounders, there was no significant association between residential location and the level of overall patient-centred care received (p=0.963). However, there were some factors associated with the receipt of patient-centred care including gender, age, cancer stage at diagnosis and cancer type. The treatment centre site was significant, with patients from a rural recruitment site (site 3) reporting lower levels of care than those from a larger urban reference site (coefficient –2.203, p=0.048).

The final model was tested for collinearity and confounding. Residential location and treatment centre site were investigated for collinearity. Although a chi-square test indicated they were significantly associated (p = <0.001), there was no evidence of collinearity, with the VIF scores below 10 (1.08–2.77) and tolerance scores were above 0.1 (0.36–0.93). Therefore, both the residential location and treatment centre site were retained in the final model. The interactions between treatment centre site and residential location were also tested for potential confounding and there were no significant interactions (rural: p=0.749; site 2: p=0.827; site 3: p=0.080; and site 4: p=0.059).

Discussion

Main findings

This study highlighted that gaps in the delivery of patient-centred care occurred for both rural and urban dwelling cancer patients during active treatment. Indeed, only a small minority (5%) of cancer patients received all elements of treatment-related patient-centred care measured in our survey. The largest gaps in care were primarily for emotional, social and pratical care delivery. Specifically, most patients in treatment had not been asked by *any* staff member throughout their cancer care so far about whether they were coping at home with practical everyday tasks, had financial concerns, had worries about their families, or if they wanted to talk to someone else in a similar situation. Despite currently receiving treatment, more than a third of the participants had not been asked by *any* staff member at their last appointment about their feelings of distress, worry or sadness. This may suggest that staff within cancer services may not have adequate training or a clear role delineation regarding whose role it is to ask these questions.

Table 4. Linear regression analysis predicting the receipt of patient-centred cancer care

Characteristic / measure	Est. (95% CI)	p value
Univariate regression		**(n=430)**
Residential postcode (Urban = Ref)		
Rural	–0.276 (–1.086 to 0.533)	0.503
Multivariable regression		**(n=421)**
Residential postcode (Urban = Ref)		
Rural	0.021 (–0.856 to 0.898)	0.963
Site (1 [Urban] = Ref)		
2 (Urban)	0.256 (–0.596 to 1.108)	0.554
3 (Rural)	–2.203 (–4.38 to –0.021)	0.048
4 (Urban)	–1.052 (–2.137 to 0.033)	0.057
Type of cancer (Breast = Ref)		
Bowel	–0.244 (–1.578 to 1.090)	0.719
Haematological	0.160 (–1.065 to 1.385)	0.798
Lung	–0.238 (–1.673 to 1.196)	0.744
Other	–1.214 (–2.395 to –0.032)	0.044
Country of birth (Australia = Ref)		
Other	–0.121 (–1.064 to 0.822)	0.801
Age (18–64 = Ref)		
65+ years	–1.577 (–2.297 to –0.857)	<0.001
Highest level of education (High school or less = Ref)		
Trade or vocational training	–0.713 (–1.476 to 0.0491)	0.067
University degree	–0.018 (–1.006 to 0.970)	0.971
Gender (Female = Ref)		
Male	1.614 (0.868 to 2.360)	<0.001
Cancer stage at diagnosis (Early = Ref)		
Advanced and/incurable	–0.135 (–0.909 to 0.640)	0.733
Don't know	–1.243 (–2.264 to –0.223)	0.017
Time since diagnosis (0–3months = Ref)		
4–6 months	0.984 (–0.204 to 2.171)	0.104
7–12 months	0.187 (–1.038 to 1.412)	0.764
More than 12 months	–0.421 (–1.417 to 0.576)	0.407

Note: The overall n from the multivariable model is based on non-missing data across all factors

To what extent was patient-centred care received during active cancer treatment?

Fewer gaps were experienced regarding information provision on the actual treatment delivery and some physical side effects. Most patients reported receiving information regarding who to contact about symptoms or side effects, what sort of symptoms or side effects to watch out for, and which signs or symptoms indicate seeking urgent medical care for. However, fatigue was the least commonly asked about symptom, with a fifth of patients not being specifically asked about this. This is concerning as fatigue is a particularly prevalent and burdensome symptom during treatment[46].

These findings are consistent with other studies examining the delivery of patient-centred care that have found 'core' oncology skills such as treatment-related information provision are mostly delivered well; however, gaps in care remain for practical, legal, social and psychological care delivery[27,47]. Some studies have suggested that it is the role of the oncology treating team to regularly elicit cancer patients' emotional symptoms[27], address socio-legal concerns[47], and to provide peer support[48]. Despite the debate of care delivery within oncology settings, data suggest patients continue to be inadequately supported throughout their cancer journey[49].

Our data were collected prior to the COVID-19 pandemic, and some changes to service provision may have occurred during this period. COVID-19 restrictions may have increased psychological burden and distress for patients resulting from restrictions on support persons within healthcare facilities, cancellations of face-to-face appointments, increased use of telehealth services, and fear of contracting the COVID-19 virus when attending healthcare settings[50,51].

Given providers within the oncology setting may be limited in providing a holistic care approach for patients, other health providers, such as general practitioners (GPs) or social workers, may be better placed to fill these gaps. For instance, by managing comorbid conditions and depression in patients with cancer, GPs could provide a key element of cancer care often not assumed by many cancer specialists[52]. However, in our study we found that 31% of participants reported that their GPs were not being kept up to date about their cancer care by the oncology treating team. Actively engaging GPs in the provision of cancer care may be a gap that needs to be addressed and may be an area that warrants further investigation.

Were there differences in the receipt of patient-centred care between rural and urban patients?

Residential location was not significantly associated with the level of patient-centred care received. These results add to the growing Australian literature that suggests that there are only minor differences in the perceived level of cancer care needs in rural and urban cancer patients[29,53]. In our study, the vast majority of rural patients (n=100, 85%) travelled to urban clinics to receive their treatment. This was consistent with previous data that rural cancer patients continue to experience issues relating to travel and accessing care compared to urban patients[53]. Our results suggest oncology staff did not differentiate their care delivery for rural versus urban patients. That is, the patients' demographic background was not used as a prompt to ask additional questions about key issues experienced by rural patients, such as social, psychological or financial issues, that they would expect to be more burdensome.

While there are fewer oncology specialists and cancer support services in rural compared to urban areas, specialist oncology nurses and stronger community and family ties in rural communities may provide cancer patients with the support needed to meet additional care needs[29]. Of note, we did find that those who received treatment from the rural site also received lower levels of patient-centred care delivery. However, given the low numbers of patients from the site (n=13), we cannot draw any robust conclusions. These findings may warrant further investigation on care delivery in rural versus urban cancer clinics.

Limitations

The findings of this study should be considered in light of several limitations. Firstly, while the SPACE measure used in this study has been pilot tested and established face validity, it has not yet undergone rigorous psychometric evaluation[34]. Future studies could seek to explore preferences for care and actual receipt of care at two different time points to reduce such confounding in patient expectations and experiences. The study findings may have also underestimated the prevalence of gaps in patient-centred care delivery for patients from culturally and linguistically diverse backgrounds as only those with adequate English literacy skills were able eligible to participate. This is reiterated through the large proportion (84%) of participants in our study who were Australian born, compared to 70% from national data[54].

While this is a large sample recruited from four hospitals in NSW, there was only one rural oncology clinic included as a recruitment site, and therefore the results may not be generalisable. Despite this, the proportion of the sample of patients residing in rural areas is comparable to that of the nation's proportion[55]. The rural versus urban differences were explored at an individual patient level, rather than differences between hospitals in those settings. Our results suggest that differences could be more likely to exist in setting locations compared to patient residential location; however, the sample of the rural treatment centre in this study was not adequate to reach this conclusion. In addition, our study explored the functioning of the oncology clinic services rather than individual healthcare practitioners. While our data reflects care delivery comprising of multidisciplinary teams, they did not allow for explorations of gaps within specialities of multidisciplinary groups.

Cancer types in this study reflect those attending four oncology services in NSW at the time of recruitment; however, the participant numbers for some of the cancer types were relatively small (such as brain cancer), but generally representative. Furthermore, our data were collected between 2017–2018 prior to the COVID-19 pandemic and therefore do not take into account the evolving nature and impact of the COVID-19 pandemic on healthcare services such as the increased use of telehealth services. It is important for future researchers to consider COVID-19 associated specific gaps in care. However, it is unlikely the gaps identified in this study have been addressed for patients given increased pressure on cancer services.

Clinical implications

This study provides valuable information for outpatient oncology treatment centres. There is a need to develop strategies to improve the delivery of patient-centred care for both rural and urban dwelling Australian cancer patients in the active treatment phase. Cancer care delivery may be enhanced through quality improvement initiatives and interventions delivered by the treatment centres. Given that the gaps largely reflect practical, social and emotional care delivery, greater involvement of other healthcare professionals could also be considered to meet gaps in the provision of patient-centred care.

Conclusion

Active cancer treatment is a critical transition point in the cancer care journey, with greater symptoms, side effects and psychosocial morbidity. This study indicated that gaps in the delivery of patient-centred care occurred in both rural and urban patients receiving cancer treatment. To ensure patients are adequately supported during this critical time, healthcare systems should move beyond core services of treating the cancer, and actively seek to assist patients to identify and manage emotional, social and practical care delivery. Due to the high proportion of Aboriginal and Torres Strait Islander people living in rural NSW, future studies should seek to explore specific Aboriginal and Torres Strait Islander cultural needs and how this may impact the delivery of cancer care.

While we explored gaps in care delivery, we did not explore the barriers and enablers to these gaps. Individual treatment centres may need to address gaps in care delivery based on their staffing profiles, such as whether care could be improved via a care coordinator or greater access to a social worker. Future research could explore whether there may be a role for primary care clinicians such as GPs. Participants from this study reported significant gaps regarding their GPs being kept up to date by the treating team. This area may warrant further investigation as GPs may be well placed to fill these supportive care gaps during patients' active cancer treatment phase.

Our study captured cancer care needs specific to rural dwelling patients, including financial and psychosocial care delivery. Despite previously identified disparities in health outcomes and access to cancer care between rural and urban cancer patients, we found only minor differences in the receipt of patient-centred care across a range of 21 elements of care. It may be reassuring for rural cancer patients, who often travel long distances to access specialised care, to know that they will receive a similar level of care to that of their urban counterparts.

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Conflicts of interest

The authors declare no conflict of interest.

Ethics approval

Ethics approval was obtained from the Human Research Ethics Committee of Hunter New England (HREC/16/HNE/249).

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Youth cancer centre: evaluation of adolescents and young adults accessing an age-appropriate environment

Vanessa Mayanja • RN, BNSc, GDipAdolHlthWelb
Adolescent & Young Adult Clinical Nurse Consultant, ONTrac at Peter Mac Victorian Adolescent & Young Adult Cancer Service, Peter MacCallum Cancer Centre, Melbourne, VIC 3000, Australia

Kate Thompson • BA, BSW, MSW
Program Director, ONTrac at Peter Mac Victorian Adolescent & Young Adult Cancer Service, Peter MacCallum Cancer Centre, Melbourne, VIC 3000, Australia
The University of Melbourne, Parkville, VIC, Australia

Jeremy Lewin* • MBBS, FRACP
Medical Director, ONTrac at Peter Mac Victorian Adolescent & Young Adult Cancer Service, Peter MacCallum Cancer Centre, Melbourne, VIC 3000, Australia
Sir Peter MacCallum Department of Oncology, The University of Melbourne, VIC, Australia
Email Jeremy.Lewin@petermac.org

**Corresponding author*

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Abstract

A key aspect of developmentally appropriate healthcare is the provision of age-appropriate environments. In 2016, the Youth Cancer Centre (YCC) located at Peter MacCallum Cancer Centre was built as an ambulatory hub for adolescent and young adults (AYA). This study examined what components of the YCC built environment were utilised and which aspects could be improved. Two questionnaires (AYA; carers) were developed that evaluated the YCC using quantitative analysis. In total, 81 individuals participated (n=49 AYA; n=32 carers). The most common reasons for YCC usage included: to attend clinical appointments with the AYA team; to use the kitchen facilities; to rest/relax; and to attend group programs and watch TV. The lack of peer connection and the ability to rearrange the space to suit individual needs were potential gaps identified by both cohorts. There is an ongoing need for research into the role of age-appropriate healthcare environments and their effect on the patient experience.

Introduction

Adolescence is a life stage marked by transition and critical growth across a number of biological, psychological and social domains[1]. While a cancer diagnosis is challenging in any life stage, in this age group, it can significantly disrupt these critical developmental transformations, having far-reaching impacts on physical growth, fertility, identity, self-esteem, mental health, relationships, education and employment, and future prospects[1,2].

Global recognition of the substantial disease burden and unique psychosocial issues experienced by young people has resulted in efforts to promote adolescent and young adult (AYA) cancer service reform, drive research and invest in clinical education[3–5]. Though widely used, the concept of age-appropriate care has not yet been clearly defined. However, the literature to date has articulated a wide range of core aspects, including: access to the best treatment; clinical and holistic expertise; recognition of young peoples' individuality; developmentally appropriate language and communication; the empowerment of young people; and youth-friendly physical and social environments[4,6].

Recent studies into the "healing architecture" of purpose-built healthcare environments show there is no consistent definition of the term nor any one architectural feature that can be linked to specific health outcomes[7,8]. Furthermore, despite emergent research on how the physical environment affects the wellbeing of individuals in the hospital environment, AYA are often overlooked[9]. Although the environment is generally considered a crucial component of age-appropriate care, it is unclear what constitutes an age-appropriate physical environment. Nonetheless, a wide range of elements require consideration, including décor, space, comfort, structure, function and flexible use of the facilities[6,9]. This differs from social environments which refer to the access of recreational activities and the mechanisms promoting peer connection for support and comfort[6].

A need to focus on the environment of care is documented in the literature where AYA reported unmet needs including access to age-appropriate treatment facilities, recreational activities and peer support[4,10]. Attempts to meet these unmet needs varies across jurisdictions and within health services. Internationally, some institutions have looked to the inpatient built environment and designed AYA-dedicated treatment centres as a component of youth-friendly cancer care[6,11]. Regardless of the setting, AYA have identified these key aspects in an age-appropriate environment: a focus on recreation, distraction, relaxation, studying, privacy, and peer connection[10,12].

The 2016 redevelopment of the Peter MacCallum Cancer Centre in Melbourne saw the build of a dedicated ambulatory Youth Cancer Centre (YCC). Co-designed with young people, the environment aimed to offer comfort, support, peer connection and recreational programs with co-location of a specialist AYA clinical service. The YCC includes consulting rooms, a fully equipped kitchen, patient lounge, entertainment rooms, privacy nooks, and dedicated spaces for school, study and work consultations, recreation and group activities.

This study aimed to examine what key aspects of the YCC built environment were utilised by young people with cancer (aged 15–25) and their friends, families and carers (henceforth 'carers'), and what further refinement is required for both the environmental design and programs delivered within.

Method

Design and measure

This study was approved by Peter Mac Human Research Ethics Committee (HREC 19/152L). The study adopted a survey design utilising a purpose-built questionnaire for both young people and their carers. Due to the absence of validated measures, the questionnaire was informed by the original design brief of the YCC as well as a review of literature surrounding health environments. The modified questionnaire for both cohorts consisted of two sections (for the AYA version see Supplemental Information). The first section sought demographic information including age, gender identity, patient or carer role status, diagnosis, place of residence, and frequency of visits to the YCC. The second section comprised of eight questions relating to the physical design and how respondents used the YCC. A space for free text was provided, enabling respondents to provide detail on how this occurred and their preferences. A 6-point Likert-type scale assessment was included to understand the experience for visitors when spending time in the YCC. Two open questions sought additional feedback and comments to complete the questionnaire.

The questionnaire captured data on which aspects were utilised by respondents, how they were used, and general feedback to assist with further refinement of the environment and programs delivered within. Quantitative questions were supported by open ended questions that identified additional key aspects of the YCC. Statements related to Likert scale questions encompassed perceptions of cleanliness, control over the environment, comfort, privacy, positive distraction, support and connectedness to others.

Respondents and recruitment

Eligible participants included all young people aged 15–25 years with cancer and their carers attending the YCC. Eligible participants presenting to the YCC were invited to participate in this study by YCC administrative staff.

Data collection and analysis

The questionnaires were available on paper and electronically. The format of the online questionnaire was hosted through REDcap, a secure web-based application designed to support data capture for research studies. All data captured on paper was transposed into REDcap.

Recruitment commenced in September 2019; however, this was placed on hold in March 2020 due to the COVID-19 pandemic. Recruitment recommenced in the first 3 months of 2021 with a total 9 months of recruitment. A total of 81 respondents returned the questionnaire for analysis.

Data analysis was performed using descriptive statistics to describe the total sample and delineate answers from the questionnaire. A thematic analysis of qualitative responses was not conducted. However, responses from open ended questions were used to support findings from the quantitative data. An analysis of Likert-style questions treated the responses as ordinal data measuring their frequency to determine the degree of respondent agreeability with each statement[13].

Results

The sample consisted of 49 AYA aged 18–28 years and 32 carers (Table 1).

AYA characteristics

There was representation across common cancer diagnoses seen in AYA with higher numbers of young people with bone and soft tissue and haematological cancers. The majority of AYA (69%) resided in a metropolitan area at the time of response, were university students (31%) or were working at the time of survey (49%), and 29% were unemployed. For those undertaking university study, there was an even split between those with a full-time or part-time enrolment status, and one respondent was in an internship. As shown in Table 2, 84% of AYA were outpatients at the time of response, with 59% at Peter Mac for after-treatment follow-up with their oncologist. Responses on the frequency of visits showed 40% of AYA visited the YCC 2–4 times a month compared to 21% visiting multiple times per week.

Reasons for attending the YCC

The most common reasons for attending the YCC were to utilise the kitchen facilities to prepare and eat meals, watch TV and

Table 1. Respondent demographics (percentages reflect those who responded to the individual question)

	AYA	Carers
No. respondents	49	32
Mean age (range)	22 (18–28 yrs)	46 (20–60 yrs)
Gender		
Male	24	7
Female	24	24
X	1	0*
Postcode		
Metro	69%	45%
Regional	23%	42%
Interstate	8%	13%
Education/employment status		
High school	4%	0%
TAFE student	8%	0%
Uni student	31%	3%
Working	49%	71%
Unemployed	29%	7%
Homemaker	2%	23%
Other	2%	7%
Cancer diagnosis		
Lymphoma	19%	N/A
Leukaemia	12%	N/A
Sarcoma	42%	N/A
Germ cell	7%	N/A
CNS	2%	N/A
Endocrine	5%	N/A
Breast	2%	N/A
Non-malignant	5%	N/A
Other	7%	N/A

* One carer did not respond to all the questions and did not identify a gender

Table 2. Respondent demographics (percentages reflect those who responded to the individual question)

	AYA	Carers
Patient treatment status at time of survey		
Under investigations	14%	10%
Active treatment for cancer	27%	60%
Follow up with oncologist	59%	30%
Patient admission status		
Inpatient	16%	19%
Outpatient	84%	81%
Mean frequency of visits to centre		
Multiple visits a week	21%	32%
2–4 times a month	40%	23%
Once a month	27%	19%
3–4 times a year	4%	13%
1–2 times a year	2%	10%
First time here	6%	3%

movies, and attend clinical appointments with members of the AYA clinical team. A total of 47% of AYA attended the YCC to participate in group programs (Figure 1).

One AYA stated:

> *Grabbing snacks from here is great. Having lunch is good here too. Jumping into the rooms for appointments with [AYA team members].*

Another highlighted:

> *I come to the YCC primarily now as a space to kill time between appointments and relax and nap (if I came in on the early flight).*

Another reported entering the YCC for multiple reasons:

> *[I] attended workout sessions, borrowed board games, came to [the] look good feel better workshop [a body confidence group workshop] and often used the kitchen to make myself tea.*

Usage of the YCC

AYA reported using the built environment of the YCC in several ways, with 70% socialising with family and friends, nearly 90% for relaxation activities, and over 60% to spend time alone (Figure 2). Other reported uses include for work or study, connecting with others and accessing information.

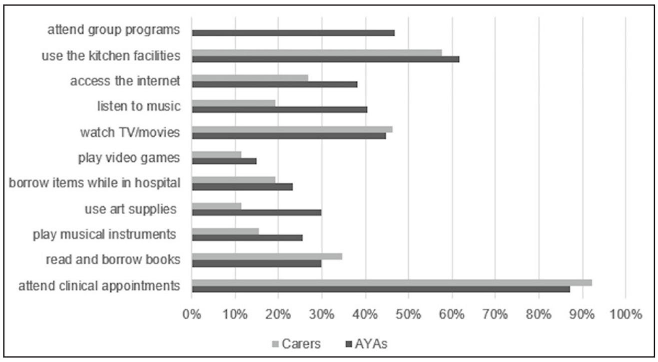

Figure 1. Reason to attend the YCC

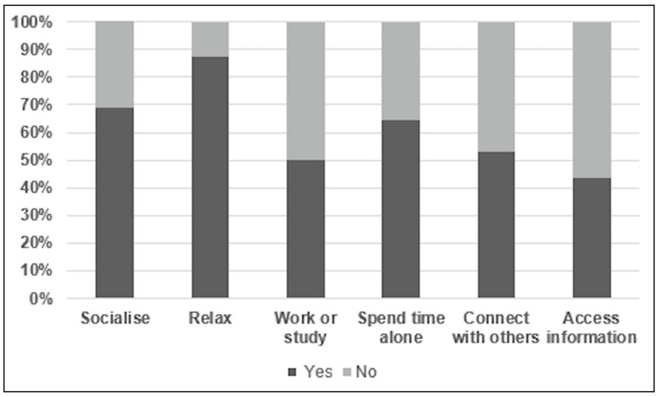

Figure 2. Ways in which the YCC is used by AYA

One AYA stated:

> *I'm a communications coordinator. The space meant I could work in between appointments so I didn't lose work hours.*

As described by this young AYA, the YCC offered:

> *... quiet, calm, a lot of space, away from the general busyness of the hospital. A great place to relax.*

This AYA reported:

> *... used the space during treatments while admitted. [I] attended events with friends & family such as Christmas.*

Perception of experience in the YCC

AYA were provided statements on the YCC environment to rate on a 6-point Likert scaling from 'strongly disagree' to 'strongly agree' (see Supplemental information for the full statements). The results are depicted in Figure 3. The three statements with the highest rates of agreeability were that the YCC environment made them feel more comfortable, had a pleasant smell, and was kept clean and in order. Statements that received the lowest rates of agreeability centred on whether the YCC could be rearranged to suit individual needs and whether it promoted feeling connected to others.

Carers

Table 1 summarises the demographic characteristics of the carer sample, a near even split between regional (42%) and metropolitan (45%) residency status, with 71% of carers employed at the time of participation. A total of 60% of carers reported that they were caring for someone on active treatment for cancer. Over 80% of carers reported they were accompanying outpatients and 32% of carers reported visiting multiple times a week (Table 2).

Reasons for attending the YCC

Carers reported a variety of reasons to attend the YCC. The most common were to use the kitchen facilities to prepare and eat meals, to watch TV and movies, and to attend clinical appointments with members of the clinical team (Figure 1).

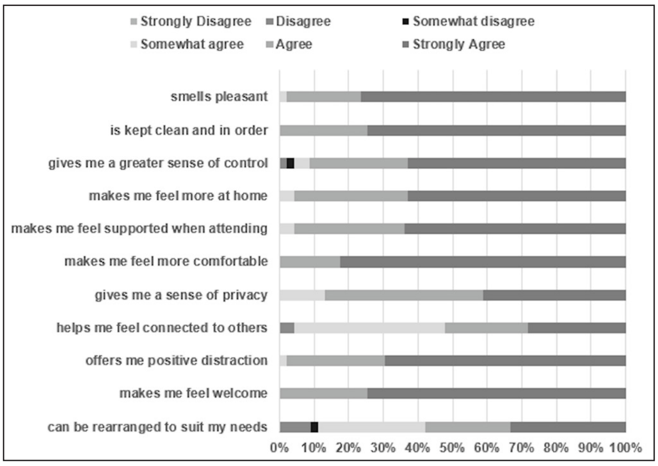

Figure 3. Perception of experience in the YCC by AYA

Carer responses offered a focus on the family inclusivity of the environment. In attending the YCC, one carer stated:

> *... [my] youngest daughter [could] play music instruments. An escape from the ward to try to make things 'normal'. Cooking, movies, sitting on bean bags, snack foods.*

Another explained visiting the YCC to make use of the kitchen facilities:

> *... prepared specific dietary meals whilst daughter on ward, heat meals when visiting.*

As stated by this carer:

> *... we go to the YCC while waiting for appointments e.g. physio & when early for other appointments.*

Usage of the YCC

We asked carers the same question relating to how the space was used (Figure 4). A total of 60% of carers reported using the YCC for socialising and about 85% of carers indicated using the space for rest and relaxation activities. Less than 40% of carers reported using the YCC to connect with others. It is noted that not all carers held a parent–child relationship with AYA.

For example, one carer used the YCC for:

> *... waiting quietly while my partner is in private appointments. Just in one of the quiet nooks.*

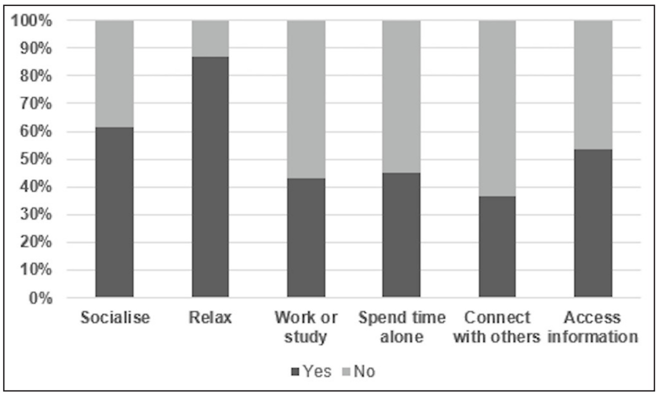

Figure 4. Ways in which the YCC is used by carers

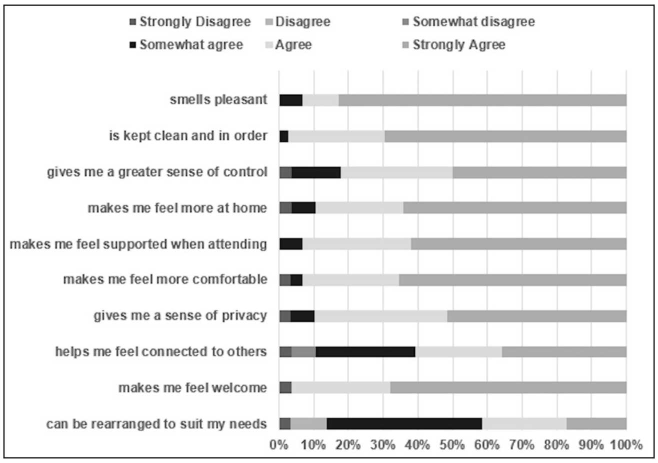

Figure 5. Perception of experience in the YCC by carers

Another carer described visiting for:

> *My daughter [sat] VCE exams under supervision. Complete SACS and subject tasks.*

Here another carer described using the YCC to access distraction opportunities:

> *… [we] often came in during my son's treatment to play games with him and interact with other young patients.*

Perception of experience in the YCC

Carers were provided similar statements to rate on the same Likert scale and returned varied agreeability in their responses (Figure 5). The statements that received the highest rates of agreeability were that the YCC environment smells pleasant, provides a sense of feeling welcome, and is kept clean. Statements that received the lowest rates of agreeability for carers centred on whether the YCC can be rearranged to suit individual needs and if it promoted a sense of connection to others.

Additional feedback from both groups

The questionnaire provided respondents with the opportunity to provide general feedback and suggestions for improvement. One carer highlighted their families' involvement with the clinical team and that they benefitted from their proximity to the environment. Another carer described their experience in the space as their friend underwent treatment and how they found opportunities to maintain normality. Several commented on how the YCC provided an opportunity to remain connected to friends, participate in family events, and celebrate milestones and holidays in the hospital. One AYA requested refinement of available amenities in food and in technology for better internet access and another highlighted some of the impacts of COVID-19 on opportunities to connect with peers.

> From carer
> *The AYA [clinical] team do an amazing job, supporting my child (young adult) and family. Always friendly and knowledgeable and very accommodating. [The YCC] compliments the team, providing an inviting, warm environment to support our family during our illness.*
>
> From AYA
> *The space provides a nice, separate escape from the crowded/clinical feel of the rest of the hospital. It's nice to have somewhere more private & comfortable to wait or take some time out.*

Discussion

This study built on the findings of a 2019 national cross-sectional study of Australian cancer services and the delivery of developmentally appropriate care to AYA. While Australian cancer services are doing well in several domains, Sawyer and colleagues demonstrated gaps in the appropriateness of physical and social environments for AYA and the need for future evaluation of dedicated co-designed spaces[4]. This current study reports how AYA and carers used a dedicated environment within the adult hospital setting and highlighted potential areas for refinement. Findings showed that AYA utilise the YCC to socialise, relax and eat, and to also access a specialist adolescent clinical service and group programs.

For both AYA and carers, the YCC was described as a place of respite from the broader hospital environment. Where AYA and carers may travel from regional or interstate areas, or require multi-day stays in hospital to access cancer treatment[2], the YCC may serve as a place to prepare meals or seek solitude as commented by several respondents. The emphasis on the role of using the YCC as a place to be away from the busyness of medical treatment rooms and hospital staff, asks for accessibility to the environment for both inpatients and outpatients. Results indicated that the perceived benefits of visiting the YCC provided an increased sense of feeling more comfortable, at home, and in control in the YCC compared to the broader hospital setting. The results also demonstrated that the YCC built environment provides mechanisms for AYA and carers to engage in distraction, relaxation, recreation, work, study, time alone, and for some peer connection. This may be especially important for those spending multiple days away from their home environment to access treatment.

Aspects of the physical environment like tables and privacy cubicles with desks were described by respondents as serving a functional use and promoting engagement in educational and vocational pursuits while attending hospital. Furthermore, both AYA and carers indicated there being a complementary experience of accessing clinical team members within the environment. The role of education and vocation advisors in minimising emotional distress for both AYA and parents, and balancing education/employment commitments with cancer care, is an example of this[14]. As one carer highlighted, their child sat Year 12 exams in the YCC, helping complete secondary schooling qualifications. For this family, both the YCC environment and the support of the clinical service may have allowed the AYA to complete educational milestones in line with age-matched peers. Completing this qualification is one of several pathways for young people to expand opportunities for employment, further training and tertiary education, and educational and vocational support may improve AYAs' financial security and quality of life beyond cancer[1,15,16]. Further research is needed to understand the benefits of accessing a whole range of specialists within the YCC, and the interplay between a clinical service and the design of the built environment.

Areas highlighted for refinement in both groups centred on the ability to rearrange the YCC to suit individual needs and feel connected to others. This alluded to the notions of comfort, social support, distraction, control and autonomy, and how the built environment influences these experiences through flexibility, sensory elements and freedom of choice[4,9]. Some features in an age-appropriate environment for AYA may meet at the intersection of the physical environment, referring to the spatial or interior design, and the social environment or social-functional characteristics of the facilities[6]. Access to recreation, entertainment, internet, distraction, relaxation, privacy, and peer connection must require consideration of both the physical environment, how it's used, and the perception of the users[4,6,10,12]. However, while the design of the physical environment may provide functional opportunity and activity space, feedback from respondents in both groups indicated that solely providing a physical environment may not be enough to facilitate peer support and meeting others who can relate to their experience. While respondents reported attending or using the YCC to socialise or connect with others, it is clear there is room for improvement in this area. Perhaps facilitation through group programs or development of other mechanisms is required to deliver social support for AYA and carers alike. This also raised questions as to the benefits of co-locating a clinical service to deliver such initiatives.

We acknowledge several limitations for this study. Firstly, this study has a small sample size with recruitment periods that occurred at the same time of COVID restrictions and thus may have had an effect on the responses received such as the availability of group programs. In addition, inherent to surveys of this nature, is the potential for selection bias with individuals, with positive experiences and regular engagement with the clinical team more likely to participate. Despite these limitations, this is the first publication of our knowledge to assess and present the uptake and use of a dedicated YCC.

In summary, the overall results emphasised that the YCC is a versatile setting with multi-purpose uses for both AYA and carers. Top reasons to attend included clinical appointments, group programs, and the use of the kitchen facilities. Young people and their families often use the space to relax and socialise. The study highlighted perceived benefits in the comfort and homeliness of the physical environment, areas for improvement in delivering peer connection opportunities, and a need for respite from the broader hospital environment for both AYA and carers. Additional research in this population is required to understand the relationship between the physical and social environment, its impact on patient and carer experience, as well as the value of co-locating a clinical service within these age-appropriate facilities.

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Conflicts of interest

The authors have declared that no conflicts of interest exist.

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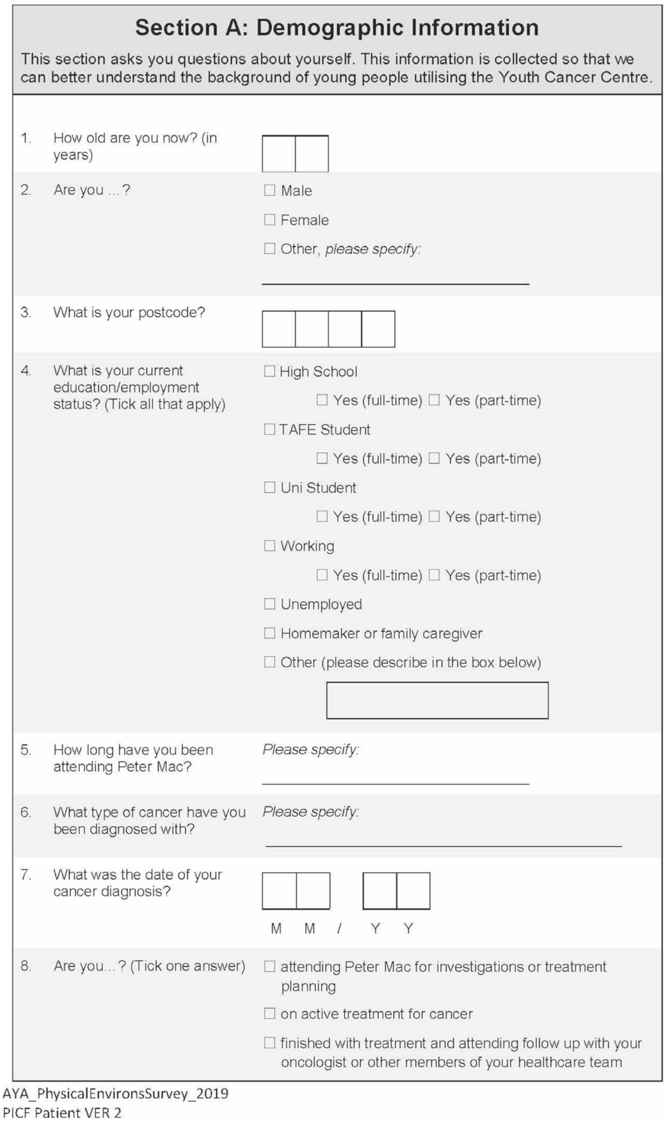
Supplementary information. AYA questionnaire

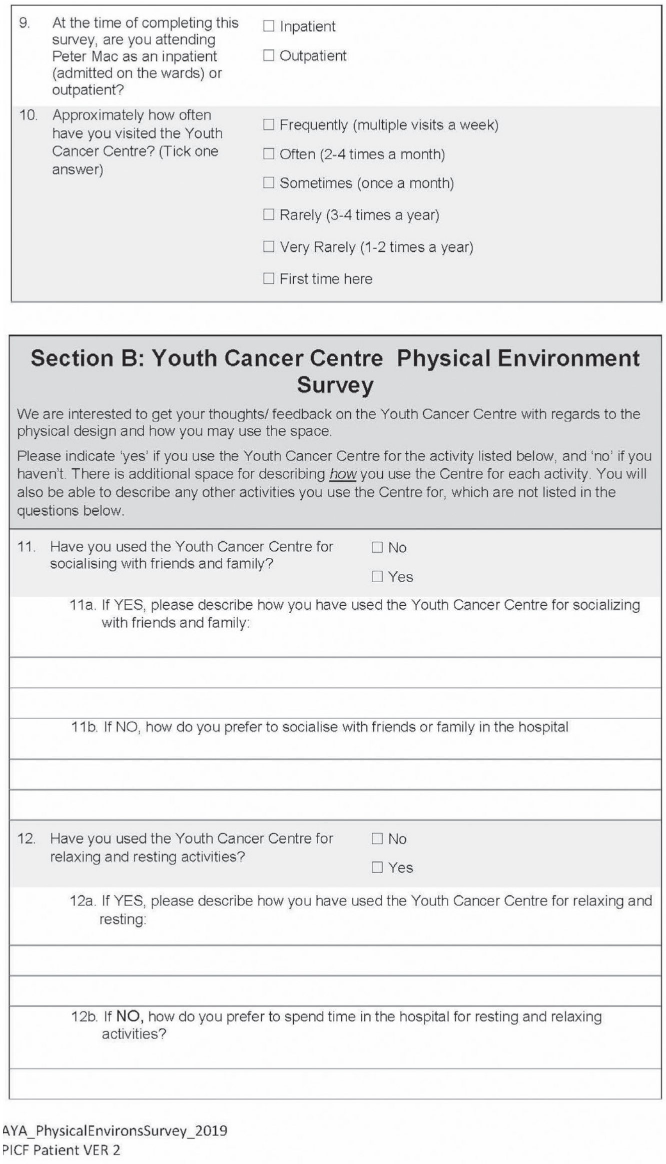


Section A: Demographic Information

This section asks you questions about yourself. This information is collected so that we can better understand the background of young people utilising the Youth Cancer Centre.

1.	How old are you now? (in years)	☐☐
2.	Are you ... ?	☐ Male ☐ Female ☐ Other, *please specify:* ____________
3.	What is your postcode?	☐☐☐☐
4.	What is your current education/employment status? (Tick all that apply)	☐ High School ☐ Yes (full-time) ☐ Yes (part-time) ☐ TAFE Student ☐ Yes (full-time) ☐ Yes (part-time) ☐ Uni Student ☐ Yes (full-time) ☐ Yes (part-time) ☐ Working ☐ Yes (full-time) ☐ Yes (part-time) ☐ Unemployed ☐ Homemaker or family caregiver ☐ Other (please describe in the box below) ☐
5.	How long have you been attending Peter Mac?	*Please specify:* ____________
6.	What type of cancer have you been diagnosed with?	*Please specify:* ____________
7.	What was the date of your cancer diagnosis?	☐☐ ☐☐ M M / Y Y
8.	Are you... ? (Tick one answer)	☐ attending Peter Mac for investigations or treatment planning ☐ on active treatment for cancer ☐ finished with treatment and attending follow up with your oncologist or other members of your healthcare team

AYA_PhysicalEnvironsSurvey_2019
PICF Patient VER 2



9.	At the time of completing this survey, are you attending Peter Mac as an inpatient (admitted on the wards) or outpatient?	☐ Inpatient ☐ Outpatient
10.	Approximately how often have you visited the Youth Cancer Centre? (Tick one answer)	☐ Frequently (multiple visits a week) ☐ Often (2-4 times a month) ☐ Sometimes (once a month) ☐ Rarely (3-4 times a year) ☐ Very Rarely (1-2 times a year) ☐ First time here

Section B: Youth Cancer Centre Physical Environment Survey

We are interested to get your thoughts/ feedback on the Youth Cancer Centre with regards to the physical design and how you may use the space.

Please indicate 'yes' if you use the Youth Cancer Centre for the activity listed below, and 'no' if you haven't. There is additional space for describing *how* you use the Centre for each activity. You will also be able to describe any other activities you use the Centre for, which are not listed in the questions below.

11.	Have you used the Youth Cancer Centre for socialising with friends and family?	☐ No ☐ Yes

11a. If YES, please describe how you have used the Youth Cancer Centre for socializing with friends and family:

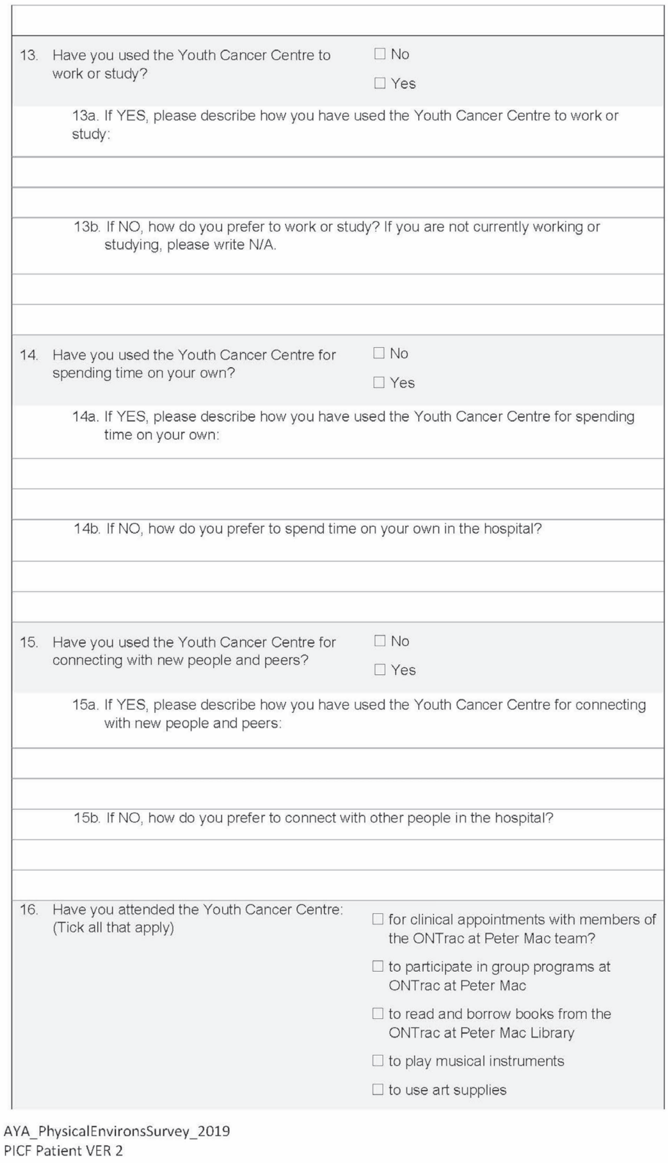
11b. If NO, how do you prefer to socialise with friends or family in the hospital

12.	Have you used the Youth Cancer Centre for relaxing and resting activities?	☐ No ☐ Yes

12a. If YES, please describe how you have used the Youth Cancer Centre for relaxing and resting:

12b. If **NO**, how do you prefer to spend time in the hospital for resting and relaxing activities?

AYA_PhysicalEnvironsSurvey_2019
PICF Patient VER 2



13. Have you used the Youth Cancer Centre to work or study?
☐ No
☐ Yes

13a. If YES, please describe how you have used the Youth Cancer Centre to work or study:

13b. If NO, how do you prefer to work or study? If you are not currently working or studying, please write N/A.

14. Have you used the Youth Cancer Centre for spending time on your own?
☐ No
☐ Yes

14a. If YES, please describe how you have used the Youth Cancer Centre for spending time on your own:

14b. If NO, how do you prefer to spend time on your own in the hospital?

15. Have you used the Youth Cancer Centre for connecting with new people and peers?
☐ No
☐ Yes

15a. If YES, please describe how you have used the Youth Cancer Centre for connecting with new people and peers:

15b. If NO, how do you prefer to connect with other people in the hospital?

16. Have you attended the Youth Cancer Centre: (Tick all that apply)
☐ for clinical appointments with members of the ONTrac at Peter Mac team?
☐ to participate in group programs at ONTrac at Peter Mac
☐ to read and borrow books from the ONTrac at Peter Mac Library
☐ to play musical instruments
☐ to use art supplies

AYA_PhysicalEnvironsSurvey_2019
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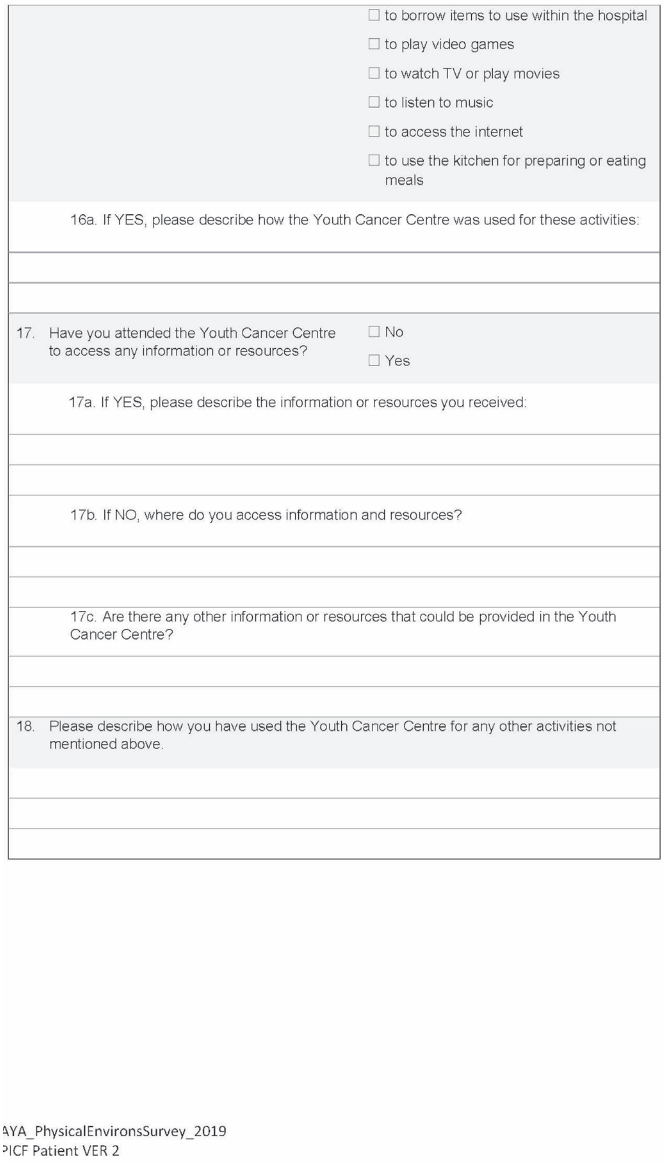


☐ to borrow items to use within the hospital
☐ to play video games
☐ to watch TV or play movies
☐ to listen to music
☐ to access the internet
☐ to use the kitchen for preparing or eating meals

16a. If YES, please describe how the Youth Cancer Centre was used for these activities:

17. Have you attended the Youth Cancer Centre to access any information or resources?
☐ No
☐ Yes

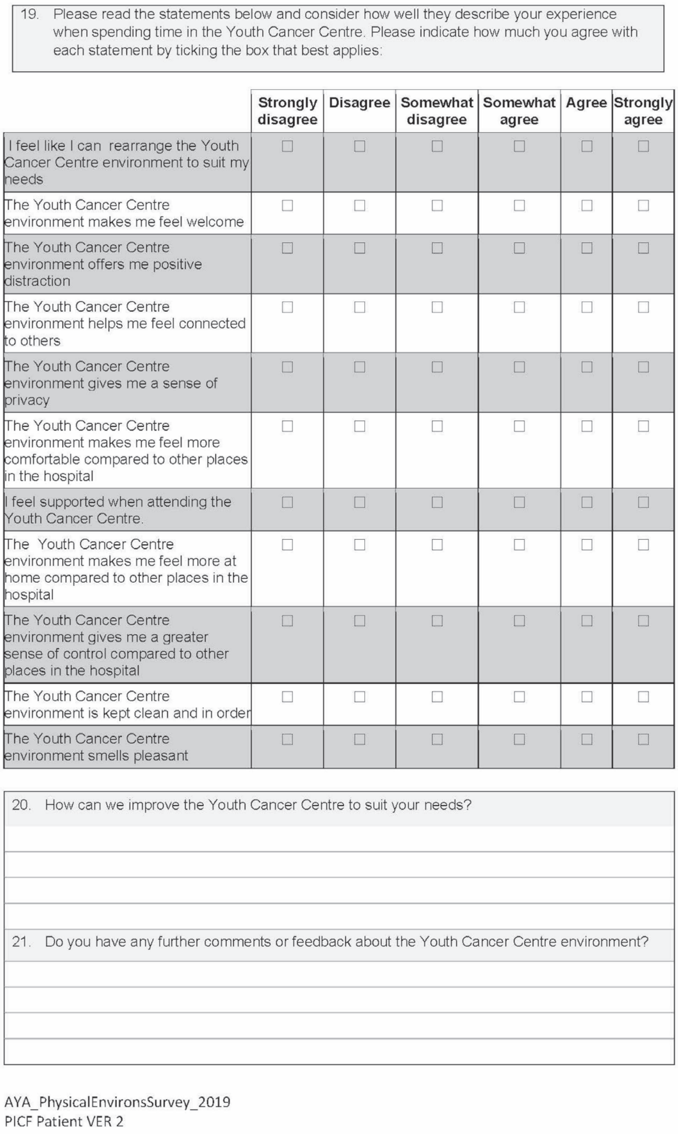
17a. If YES, please describe the information or resources you received:

17b. If NO, where do you access information and resources?

17c. Are there any other information or resources that could be provided in the Youth Cancer Centre?

18. Please describe how you have used the Youth Cancer Centre for any other activities not mentioned above.

AYA_PhysicalEnvironsSurvey_2019
PICF Patient VER 2



19. Please read the statements below and consider how well they describe your experience when spending time in the Youth Cancer Centre. Please indicate how much you agree with each statement by ticking the box that best applies:

	Strongly disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly agree
I feel like I can rearrange the Youth Cancer Centre environment to suit my needs	☐	☐	☐	☐	☐	☐
The Youth Cancer Centre environment makes me feel welcome	☐	☐	☐	☐	☐	☐
The Youth Cancer Centre environment offers me positive distraction	☐	☐	☐	☐	☐	☐
The Youth Cancer Centre environment helps me feel connected to others	☐	☐	☐	☐	☐	☐
The Youth Cancer Centre environment gives me a sense of privacy	☐	☐	☐	☐	☐	☐
The Youth Cancer Centre environment makes me feel more comfortable compared to other places in the hospital	☐	☐	☐	☐	☐	☐
I feel supported when attending the Youth Cancer Centre.	☐	☐	☐	☐	☐	☐
The Youth Cancer Centre environment makes me feel more at home compared to other places in the hospital	☐	☐	☐	☐	☐	☐
The Youth Cancer Centre environment gives me a greater sense of control compared to other places in the hospital	☐	☐	☐	☐	☐	☐
The Youth Cancer Centre environment is kept clean and in order	☐	☐	☐	☐	☐	☐
The Youth Cancer Centre environment smells pleasant	☐	☐	☐	☐	☐	☐

20. How can we improve the Youth Cancer Centre to suit your needs?

21. Do you have any further comments or feedback about the Youth Cancer Centre environment?

AYA_PhysicalEnvironsSurvey_2019
PICF Patient VER 2

Exploring the educational needs of non-specialist cancer nurses who provide care for people with cancer: a mixed-methods study

Jessica Balson* • RN, MAdvNursPrac
Nurse Unit Manager, Western Health, 176 Furlong Rd, St. Albans, VIC 3021, Australia
Email jess.balson@gmail.com

Mei Krishnasamy • RN, PhD
Professor/Director, Academic Nursing Unit, Peter MacCallum Cancer Centre, Peter MacCallum Cancer Centre Level 7, 305 Grattan Street, Melbourne, VIC 3000, Australia

Sara Holton • PhD
Senior Research Fellow, Centre for Quality and Patient Safety Research – Western Health Partnership, School of Nursing and Midwifery, Faculty of Health, Deakin University, Building Y, 221 Burwood Hwy, Burwood, VIC 3125, Australia

Bodil Rassmussen • PhD
Chair in Nursing (Western Health), Centre for Quality and Patient Safety Research – Western Health Partnership, School of Nursing and Midwifery, Faculty of Health, Deakin University, Building Y, 221 Burwood Hwy, Burwood, VIC 3125, Australia

**Corresponding author*

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Abstract

Background Non-specialist cancer nurses deliver a substantial proportion of cancer care in Australia, but report a lack of foundational education in cancer. Little is known about their educational needs.

Objectives To explore and describe the care provided by non-specialist cancer nurses and identify unmet needs regarding cancer care and education.

Design Exploratory, concurrent, mixed-methods.

Settings and participants Registered nurses working in non-specialist wards that provided cancer care in metropolitan public hospital in Melbourne, Australia.

Methods An online survey and semi-structured interview assessing care provided, nurses' experiences and education needs. Data were analysed using descriptive statistics and thematic analysis.

Results A synthesis of both data sets revealed a lack of knowledge and confidence in foundational cancer knowledge, communicating with patients, providing supportive care and delivering end of life care.

Conclusion Non-specialist nurses lack confidence and knowledge of core aspects of cancer care and would benefit from tailored education.

Background

In 2021, 151,000 Australians were diagnosed with cancer, a number projected to rise to 185,000 by 2031[1]. As the Australian population ages, the rate of cancer-related hospitalisations is projected to increase[1]. To address the increasing demand for hospital inpatient capacity, patients are often placed on wards that are not designated for their particular disease, illness or treatment, and as such they may not be cared for by nurses who are experienced in that particular disease or illness.

These patients are referred to as 'outliers' and can account for up to 10% of admitted inpatients at any given time[2]. Patients admitted to outlier wards have been reported to have longer lengths of stay and are at greater risk of emergency calls, readmissions and poorer health outcomes compared to patients cared for in speciality units[2]. The allocation of cancer patients with specialist care and treatment needs to outlier wards presents many challenges for non-specialist cancer nurses who may feel unable to provide what they believe is an appropriate level of care within their scope of practice. Non-specialist nurses have cited a number of challenges when caring for people with a cancer diagnosis. These include the highly emotional nature of cancer care, lack of time to attend to patients' psychosocial needs, lack of knowledge of cancer treatment, lack of skills to provide family support, lack of appropriate resources and dealing with patients' fears, and anxieties regrading a cancer diagnosis[3,4].

In Australia, as elsewhere in the world, the paucity of cancer education in undergraduate nursing programs has been shown to influence nurses' feelings of inadequacy when caring for people with cancer[3,5,6]. As the number of people affected by a cancer diagnosis continues to increase[7], most nurses, irrespective of the care setting, will care for a person with cancer at some time[6]. Studies exploring the educational needs of non-specialist cancer nurses in the United Kingdom[6,8,9] and the United States[5,10] have reported the need for essential education for nurses about basic cancer knowledge, communication, psychological support and end of life care. In 2005, Mohan et al.[3] explored the learning needs of non-specialist Australian nurses in cancer care and identified six major themes – the emotional nature of care, lack of time, lack of knowledge of cancer treatment, family support, environment not conducive to proper care, and dealing with patients' non-acceptance of cancer diagnosis. Yet since the publication of these findings, there has been no further published work reporting on their education needs, despite remarkable advances in cancer therapies with corresponding care needs. Our study sought to address this gap in research and explore the current educational needs of Australian nurses.

A specialist cancer nurse has been defined as a nurse working in a dedicated cancer hospital or a ward/unit/service that provides care specifically to people with cancer and/or holds a post-graduate cancer nursing qualification[8,11]. A non-specialist cancer nurse has been defined as a nurse working in a general hospital or health service that may include people with cancer or who works in a ward/unit/service that includes oncology/haematology as one of its specialties. It also incorporates graduate nurses working in a dedicated cancer hospital/ward/unit/service[3,4,6,12].

Aim and objectives

The aim of this study was to explore the educational needs and care provided by non-specialist nurses to patients with cancer. Objectives included exploring and describing key components of nursing care provided by non-specialist nurses to people with cancer and identifying nurses' unmet educational needs about cancer and cancer care.

The following research questions were devised:

- Which components of cancer care are non-specialist nurses involved in and how do they experience the provision of cancer care?
- Do non-specialist nurses feel confident when caring for people with cancer and which factors affect their confidence?
- Which aspects of care do non-specialist nurses consider to be areas of educational need?
- How do non-specialist nurses prefer to access cancer nursing education?
- What are the barriers and enablers to accessing cancer nursing education?

Methods

Study design

The study used an exploratory, concurrent mixed-methods approach[13] to enable a more complete understanding of the phenomenon of interest[14]. A concurrent approach to data collection was chosen to enable consideration of quantitative and qualitative data sets alongside each other, with data integration occurring during analysis and reporting[15].

This study was undertaken in part-fulfilment of a Master of Advanced Nursing Practice. The study protocol was approved as a Low and Negligible Risk application by the participating site's Human Research Ethics Panel (ID 67645) based on the ethical standards of the Australian National Statement on Ethical Conduct in Human Research. This study has been reported in accordance with the Good Reporting of A Mixed-Methods Study (GRAMMS) checklist[16].

Setting, sample and recruitment

The setting for this study was a large metropolitan public health service in Melbourne, Australia that provides inpatient cancer care to over 1,000 people annually across non-specialist cancer wards[17].

A convenience sample of 262 nurses from six wards were approached to take part in one anonymous, online survey and one audio-recorded qualitative interview. Wards were selected as those having the highest number of admitted oncology patients within the organisation. Nurses were invited to participate in both the online survey and interview via an email sent by the nurse unit manager to their nursing team. The email contained a link to the anonymous online survey, ensuring that the nurse unit manager had no knowledge of which members of the team did or did not participate, reducing risk of coercion. Potential participants were made aware that they could choose to take part in the survey and interview, only the survey, only the interview or in neither. Nurses were asked to contact the researcher if they were interested in taking part in the interview.

Nurses were eligible to participate in the study provided they were working on one of the six wards selected and had at least 1 year of experience post-registration. Nurses with post-graduate qualifications in cancer nursing were excluded as they did not fit the definition of a non-specialist cancer nurse; however, those with post-graduate qualifications in other areas were included. Enrolled nurses were also excluded because of the difference in their level of pre-registration preparation.

Survey

A study-specific, online survey was developed based on survey questions used by Mohan et al.[3], a review of relevant literature, and the researchers' clinical expertise. The survey was pilot tested among five nursing staff members to ensure comprehension and acceptability before it was distributed to potential respondents; these nurses were not included in the study sample. The online survey was hosted on the platform Qualtrics[18] and consisted of 15 fixed-response questions, including multiple choice questions and Likert scales focusing on cancer care and nursing education (Figure 1).

The type and frequency of care provided to patients with cancer
Self-perceived levels of competency and confidence
Whether they found the work to be distressing or emotional
Level of knowledge of cancer concepts
Desire for further education
Likeliness to address their educational needs
Use of specific educational resources and delivery formats
Perceived barriers and enablers to educational support

Figure 1. Survey question topics

Respondents' sociodemographic characteristics – including age, years since qualifying as a nurse, years working at the study site, role and professional qualifications held – were gathered. A copy of the survey is available from the corresponding author by request.

Interview

Qualitative data were collected using audio-recorded, semi-structured interviews to collect more detailed data about nurses' perceptions and experiences of providing care for cancer patients, and their educational needs and preferences. Interviews took place in person or via Zoom[19]. An interview schedule was developed using a similar format to the survey in order to explore the same topics in further detail. The use of a schedule ensured consistency of questioning across participants. Interviews were transcribed verbatim using Otter.ai transcription software[20] and checked for accuracy.

Data analysis

Quantitative data were collected and analysed descriptively, including frequency, ranges, means and proportions. Some responses to Likert-scale items were combined to binary variables for data analysis. These included combining responses of 'not confident' and 'somewhat confident' to distinguish nurses who felt confident and those who did not feel confident. Responses of 'somewhat' and 'very' emotional/distressing were grouped to identify those who found the work to be emotional or distressing compared to those who did not. Responses of 'no knowledge' and 'some knowledge' were grouped to differentiate those who had good knowledge of a concept from those who did not.

Transcribed qualitative data were managed with the use of NVivo 12Pro software[21] and analysed using Braun and Clarke's six-phase thematic analysis approach[22]. Phase 1 and 2 involved familiarisation with the data through the transcription and re-reading of the data before codes were identified. In phase 3, codes were grouped together by themes, which were reviewed as part of phase 4. Phase 5 involved defining and naming the themes that aligned with survey questions as a way of giving meaning and interpreting the content. In phase 6, findings were related back to the research question and categorised under two main themes – Providing cancer care and Cancer education. All interviews were analysed by the first author. Half of the transcripts were co-coded by supervisors to establish inter-rater reliability and assure credibility and trustworthiness of the analytical process.

Data synthesis

Data integration occurred using a merging approach where findings and insights from both data sets were analysed alongside each other, noting the similarities and differences[15]. Insights from the quantitative and qualitative data sets were brought together following independent analysis under the two main themes: 1) exploring and describing key components of nursing care, titled Providing cancer care; and, 2) relating to identifying unmet needs regarding training, education and clinical support, titled Cancer education.

Results

In keeping with a concurrent mixed methods design, findings from the qualitative and quantitative data sets are presented together. Of the potential sample of 262 nurses, 62 (22%) nurses completed the online survey (Table 1).

Four nurses from different wards across the hospital agreed to be interviewed. Their years of clinical experience ranged from 6–20 years, and they were aged between 27–50 years of age. Two held post-graduate qualifications and all four had been employed at the study site for over 5 years.

Providing cancer care

When asked about the frequency of caring for patients with cancer, over half of nurses surveyed (n=38/61%) cared for patients with a cancer diagnosis once a week or less. The most common care activities provided were symptom relief, assisting with activities of daily living, and communicating with the patients and their loved ones (Table 2).

Table 1. Sociodemographic and professional characteristics of survey respondents (n=62)

Characteristics of respondents	n (%)
Age	
18–25 years	12 (19)
26–30 years	11 (18)
31–40 years	20 (32)
41–50 years	14 (22)
51–60 years	4 (7)
60+ years	1 (2)
Years since qualifying as a nurse	
1–2 years	11 (18)
3–5 years	13 (21)
6–10 years	14 (22)
11–15 years	15 (24)
16+ years	9 (15)
Years employed at the study site	
<10 years	49 (79)
11+ years	13 (21)
Highest post-graduate nursing qualification	
Certificate	9 (15)
Diploma	6 (10)
Masters	1 (2)
Role	
Registered nurse	45 (72)
Clinical nurse specialist	8 (13)
Associate nurse unit manager	9 (15)
Nurse unit manager	0 (0)
Ward	
Acute aged care	14 (22)
Medical (mixed specialty)	11 (18)
Cardiac / medical	19 (31)
Medical	10 (16)
Medical / neurology (re-purposed as COVID)	6 (10)
Respiratory (re-purposed as COVID)	2 (3)

When asked about their level of competence, 40 nurses (70%) identified themselves as a novice or advanced beginner when it came to providing cancer care. Nurses felt least confident when required to help patients come to terms with their diagnoses or prognoses (Table 3); nurses cited a number of factors as impacting their confidence (Table 4).

One interview participant stated:

> *Because we are not trained in oncology… sometimes we do find it a bit hard when you have to cope with the families and with the patient's emotions as well… it's quite challenging* – Interview Participant 3.

Most of the nurses surveyed found the provision of cancer care to be both emotional (n=44/81%) and distressing (n=35/73%). When asked whether they found it challenging to be present when a patient received a diagnosis of cancer, one interview participant said:

Table 2. Common care activities (n=62)

Activity of care	n (%)
Treating symptoms such as pain, shortness of breath, nausea and vomiting	47 (76)
Personal care / activities of daily living	47 (76)
Communicating with patient and loved ones	39 (63)
Care-coordination	34 (55)
Providing end of life nursing care	30 (48)
Engaging in discussions with patient about palliation / end of life care	26 (42)
Educating patients about their treatment options and side effects	25 (40)
Providing post-operative nursing care	21 (34)
Providing bereavement support for loved ones	20 (33)
Educating patients about chemotherapy-related side effects	19 (31)
Supporting patients when discussing their diagnosis	17 (27)
Rehabilitation	12 (19)
Attending family meetings to discuss changes to care/ prognosis/treatment options	9 (15)

> *Oh, I don't like it [when patient receive their diagnosis]. Especially when they're young. I just walk away. It makes me sad now* – Interview Participant 4.

Another interview participant highlighted the challenges when dealing with young cancer patients coupled with a lack of knowledge and experience in the area:

> *That's why it's more challenging and emotional as well, like when you look at young patients and their families and they ask you these sorts of questions like about [prognosis], medication, treatment and things, it's quite challenging* – Interview Participant 3.

In the absence of their own specialist knowledge, nurses described having to rely on the patient's treating team to provide information to patients and families:

> *We always just try to request the treating team to actually provide more information to their families and talk to the families and provide information to the patient* – Interview Participant 3.

Cancer education

Only eight (14%) nurses who responded to the question about level of knowledge regarding cancer chemotherapy reported that they had 'good knowledge', despite this being one of the main treatment modalities delivered to patients (Table 5).

Over half (n=37/64%) of respondents indicated that they had no or only some knowledge of cytotoxic precautions, despite the prevalence of oral cytotoxic medications and their associated risks. Surprisingly, findings were similar in topics that are not

Table 3. Confidence in undertaking care activities (n=variable)

Confidence in undertaking care activities	N	'Not' to 'somewhat' confident n (%)
Helping the patient come to terms with their diagnosis/prognosis	58	51 (88)
Explaining treatment / side effects	57	44 (77)
Dealing with side effects	58	44 (76)
Communicating with the family and loved ones	57	43 (75)
Communicating with the medical team	58	41 (71)
Communicating with the patient	58	40 (69)
Providing end of life care	58	34 (58)

Table 4. Contributing factors to lower levels of confidence (n=variable)

Factors impacting confidence	'Not' to 'somewhat' confident n (%)
Lack of knowledge about treatment and side effects	32 (62)
Lack of knowledge about cancer	30 (48)
Providing psychological support	28 (45)
Lack of knowledge relating to symptom management	7 (11)
Communication skills	4 (6)
No concerns	4 (6)
Being unable to access central lines	2 (3)

exclusive to cancer care such as infection and sepsis (n=37/64%) and cancer pain (n=44/76%).

When asked to identify areas for further education, topics were consistent with self-identified areas of low knowledge including chemotherapy (n=31/59%) and cancer pathophysiology (n=31/59%), voluntary assisted dying (n=37/68%) and sexual health (n=36/67%).

Requests for foundational knowledge about cancer and its treatments were present in interview data:

> *It would be nice if we had more education around different cancers that we see quite often on the ward. If we have a good foundation base of how that particular type of cancer affects that person's life, then our care might be better directed towards them* – Interview Participant 1.
>
> *[I would like more information about]... the side effects of the chemo medication and about the side effects of different cancers and cancer medications. I think that'd be really helpful. If we can get more information at least we can actively participate and give more information to the family and the patients* – Interview Participant 3.

Despite identifying a range of gaps in knowledge, less than a half of respondents reported being 'very likely' (n=22/40%) to address their educational needs. The majority of survey respondents (n=33/60%) reported that they would only be 'somewhat likely' or less to attend education events to address deficits in their knowledge.

Table 5. Level of knowledge of cancer concepts (n=variable)

Topic / no. times item selected	N	'No' to 'some' knowledge n (%)	'Good' knowledge n (%)
Advance care planning	58	50 (86)	8 (14)
Cancer pain	58	44 (76)	14 (24)
Cancer pathophysiology	58	47 (81)	11 (19)
Central line management	58	36 (62)	22 (38)
Chemotherapy	57	49 (86)	8 (14)
Communication	57	38 (67)	19 (33)
Cytotoxic precautions	58	37 (64)	21 (36)
Infection and sepsis	58	37 (64)	21 (36)
Management of side effects	57	48 (84)	9 (16)
Palliation and end of life care	58	30 (52)	28 (48)
Sexual health	57	55 (96)	2 (4)
Supportive care	58	48 (83)	10 (17)
Symptom control	57	40 (70)	17 (30)
Treatment options	57	52 (91)	5 (9)
Voluntary assisted dying	58	54 (93)	4 (7)

Half of the nurses surveyed highlighted the importance of having support from their nurse manager (n=31/50%) to engage in and attend educational events. Provision of education during an appropriate time such as double-staffing time (n=44/71%) was identified as a key factor in being able to access education. Awareness of educational opportunities was also identified as a key enabler (n=47/76%); however, 28 (45%) of survey respondents reported that they were not always aware of what was available, or who to speak to regarding education and support (n=21/34%). Lack of time (n=20/32%) was also reported as a barrier.

Similar challenges were also highlighted by the interview participants when asked about accessing education:

> *I think time is a major factor. I feel like you're constantly on the run, working, working, working and life gets in the way... I know all the resources are there, but I think we sort of forget to slow down and actually take the time to read over all of that* – Interview Participant 1.
>
> *Apart from a quick look up of something for a specific patient, you do most of the study at home, you do most of it in your time off. You don't have time on the floor, you run from the minute you start to the minute you finish. So, you wouldn't get time on the ward, so time would be a barrier. If you've got limited time and you're doing it in your own time, then motivation's going to be a factor* – Interview Participant 2.

Policies and procedures were ranked by almost a half (n=23/49%) of nurses surveyed as being the most useful educational resources, followed by oncology study days (n=14/30%) and support from an oncology nurse educator (n=16/34%). The majority (n=50/81%) of nurses preferred in-service sessions and attending study days (n=43/69%):

> *I prefer face-to-face education, I think I learn better, especially when we see something more hands on* – Interview Participant 1.

Discussion

Non-specialist cancer nurses in our study reported low levels of confidence and a lack of knowledge when caring for patients with cancer. Infrequent provision of cancer care resulted in a lack of exposure to aspects of care, and a lack of familiarity with discussing cancer issues with patients. While essential nursing care such as providing symptom relief and communication are considered common care activities, they were also identified as key areas of educational need by the nurses in this study and in previously reported literature[9,10]. Similarly, nurses in this study reported that a lack of knowledge affected their confidence and their ability to provide what they consider to be optimal nursing care, a finding reported in previous studies[4,9].

The majority of nurses in this study self-assessed their level of practice as a novice or advanced beginner cancer nurse, and their level of confidence in providing cancer care as low, particularly in areas such as understanding of cancer pathophysiology, treatments and side effects and providing psychosocial care. Previous studies have demonstrated that non-specialist nurses report low levels of confidence in many key areas of cancer care, particularly communication, providing psychosocial care, and dealing with treatment side effects[4,6,9]. Nurses in this study indicated that their lack of confidence stemmed from a lack of knowledge, experience and training in areas that are important in the provision of safe cancer care such as explaining treatment options, managing side effects, psychosocial care and discussing prognosis. These topics have also been identified in previous research of the learning needs of non-specialist cancer nurses[6,8,10,23].

Corner[24] described the nature of cancer care as technical and highly skilled, where nurses juggle complex physiological knowledge to inform their actions in critical situations, but noted that even when they possess specialist knowledge, specialist cancer nurses find their work to be emotionally demanding and stressful. It is unsurprising therefore, that the non-specialist nurses in this study reported experiencing cancer care as emotional and, at times, distressing.

Nurses identified a need for education in a variety of areas that were consistent with similar needs analyses such as psychosocial issues[6,8,9,11,23], symptom control[10,23], palliation and end of life care[6,10,23] and communication[8], and indicated a preference for face-to-face education. However, several barriers such as having limited time, lacking support from managers, and lacking awareness of opportunities were acknowledged as impacting the likelihood of nurses accessing education to address them. Issues such as cost and timing of education have been acknowledged as influencing non-specialist nurses' decisions to access cancer-related education[23]. As such, it is important that cancer education resources are developed in line with the known barriers and enablers to ensure they are accessible and impactful.

Implications for nursing education

This study suggests that greater investment is needed to develop tailored educational resources to meet the needs of non-specialist nurses caring for patients with cancer. As we look to diversify our workforce and expand the numbers of novice nurses entering the health system, there is an urgent need to better prepare and provide ongoing learning opportunities for non-specialist cancer nurses and to reduce the potential for distress caused by feeling inadequately prepared to provide suitable care.

Strengths and limitations

This study was conducted during the COVID-19 pandemic which affected recruitment of participants due to the increased workload of and inability to access certain nursing staff. As such, our numbers are small but our insights are informative. It is also important to note that, given this was a single site study conducted in a metropolitan setting, the findings cannot be generalised to other sites or settings.

Conclusion

This study has demonstrated the importance of investing resources into the upskilling of non-specialist nurses so that they can safely provide nursing care to the growing number of Australians diagnosed with cancer. It has identified key knowledge gaps that can be addressed through targeted education, and findings from this study are currently being used to develop an educational resource for non-specialist nurses involved in the provision of care to patients with cancer.

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Definitions

A specialist cancer nurse works in a dedicated cancer hospital OR works within a dedicated cancer ward/unit/service that provides care specifically to people with cancer AND/OR holds a post-graduate cancer nursing qualification.

A non-specialist cancer nurse works in a general hospital or community service AND works in a ward/unit/service that may include people with cancer OR works in a ward/unit/service that includes oncology/haematology as one of its specialties OR is an undergraduate OR graduate nurse working in a dedicated cancer hospital/ward/unit/service.

Conflict of interest

The authors declare no conflicts of interest.

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Systematic review of nurse-led clinics to support persons with head and neck cancer

Selina Ward* • BSc., BN, GrCert
Research Nurse, Queensland Health, QLD, Australia
ORCID: https://orcid.org/0000-0002-7776-8419
Email Selina.ward95@gmail.com

Elisabeth Coyne • BN, MN, PhD
Senior Lecturer, Griffith University, QLD, Australia
ORCID: https://orcid.org/0000-0001-8511-600X

**Corresponding author*

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Abstract

Aims The aim of this systematic review was to critique research examining the use of nurse-led clinics for head and neck cancers.

Method This review was conducted using the Pickering systematic literature review framework. Searching during November 2021, research published between 2011–2021 from the databases MEDLINE, Scopus, PsychINFO, Cochrane and CINAHL was appraised using the Mixed Methods Appraisal Tool (MMAT), descriptive quantitative analysis and thematic analysis.

Results A total of 134 articles were recovered, with 13 studies included for analysis. Of these, seven were cohort studies, four were observations-based and five were randomised control trials. Furthermore, 12 of these studies highlighted the role of an outpatient clinic-based nurse practice, and four were based on the generalised role of an advanced practice nurse. Of all 13 studies, only one was based in Australia, with the majority based in either Europe (7) or the USA (8).

Conclusion Nurse-led clinics for head and neck cancer follow ups show promising results to improve patients' quality of life. All 13 studies showed an increase in patient-reported quality of life. Further research may be required to study the financial and resource availability for the utilisation of nurse-led clinics in the future.

Impact This study addressed a gap in knowledge of the success and distribution of nurse-led clinics in the field of head and neck cancers. Overall, there is a strong outcome of feasibility and quality patient outcomes for nurse-led clinics. However, there are low sample sizes in the articles found. This may have future impacts on policy and resource funding for further development of nurse-led services; however, further research will be required.

Introduction and background

Cancers of the head and neck are not only clinically and physically complex but also present with a large array of complications both medically and psychologically[1]. Common practice for head and neck cancer treatments includes but is not limited to radiation therapy, chemotherapy, surgery, immunotherapy and targeted therapies[2]. In many cases, this often results in a short hospitalisation period followed by intensive outpatient therapy and follow up[3].

Often, radiation therapy is considered as a first line treatment for head and neck cancers; however, this is accompanied by an array of complex and harmful side effects. Early side effects may include inflammation of the mucosa, difficulty and pain on swallowing, dermatitis, and inability to obtain adequate nutrition[1]. Long-term side effects may include damage to oral and facial features, permanent lymphoedema, loss of oral function, tissue necrosis, and many more[4]. Following this, issues arising following treatment for head and neck cancer are centralised around nutrition, activities of daily living, general life satisfaction and psychological needs[5,6].

In modern medicine, the 30-day hospital readmission rate is a commonly used predictor for quality care provision and analysis of subsequent financial burden of disease[7]. In general, the 30-day hospital readmission rate is substantially higher for those undergoing radiation therapy compared to surgical treatment[8]. Utilisation of an ongoing nurse-led clinic follow up is shown to reduce hospital readmissions in head and neck cancer and influence quality of life[9]. Furthermore, nurse-led clinics are also associated with increased nurse satisfaction and retention, both are which are ever growing concerns within the healthcare economy[10,11].

From a historical context, nurse-led clinics for cancer care were envisioned as an ambulatory-based service that would aid in filling the gaps in healthcare service and delivery[12]. As an example, a nurse-led surveillance follow-up program for colorectal cancers was shown to be effective in detecting cancer recurrence and was associated with a highly regarded patient satisfaction rate[13]. Furthermore, nurse-led clinics are shown to be more cost-effective than traditional service delivery owing to reduced emergency room visits, less provider costs, shortened healthcare admissions, and less operational resource requirements[14,15]. From a patient perspective, nurse-led clinics are highly regarded financially due to less out-of-pocket expenses, reduced wait times and, in rural and regional areas, less cost for travel[16,17].

A recent scoping review of nurse-led general oncology clinics across countries in Europe, USA and Australia concludes that patient satisfaction is higher for nurse-led clinics compared to traditional physician-led clinics[9]. Studies show that nurse-led clinics redirect the focus of consultation to a patient-centered focus rather than a traditional treatment-focused approach[18-20]. A systematic review of medical-based nurse-led clinics' successful attributes shows that providing person-centred care is a key component to improving the patients' subjective experience[21]. As described by patients utilising this service, the key characteristics described as essential to the functionality of nurse-led clinics include provision of access to information, sharing of knowledge, and establishing strong therapeutic relationships[22].

The integration of nurse-led clinics in oncology care is slowly building momentum on a global scale. In 2017, a scoping review of nurse-led clinics within the past 10 years reveled 22 specific nurse-led cancer clinics, with the majority based in European countries[23]. At this point in time, it is unknown exactly how many nurse-led cancer clinics are currently operating. Research, however, does suggest that this number is continually increasing as the demand for specialised healthcare grows in regional and rural areas[24,25]. To support this development, further research is required to support policy changes and advocate on behalf of patients to obtain the required funding and resources for nurse-led clinics to operate.

Method

Aims

The primary aim of this systematic review was to explore the patient outcomes of nurse-led clinics in the field of head and neck cancer. The secondary aim of this review was to analyse the distribution and structure of current nurse-led clinics operating for head and neck cancers.

Design

This systematic review was structed using the Pickering framework[26,27] for systematic literature reviews. The Pickering framework uses a 15-step methodology to search for relevant literature, create a database of findings, and analyse data in a comprehensive and methodical way[27]. To determine suitable literature for review, Covidence was used to screen and select articles whereby the decisions were blinded between authors[28]. This process followed two screening steps. Firstly, abstract screening for eligibility and appropriate inclusion criteria. Secondly, full text screening was used to determine final eligibility for all articles. Reports were excluded if they did not fit the inclusion criteria.

Search methods

Boolean used for searching databases is as follows: (nurse-led OR nurse OR nurse managed) AND (head cancer OR neck cancer or oropharyngeal cancer OR head and neck cancer) AND (clinic OR follow-up OR ambulatory clinic). This search was then manually refined by excluding: “Nurse practitioner” OR “Rectal cancer” OR “non-head/neck cancers” OR “non-cancer patients”.

Inclusion criteria

- Full text available in English.
- Nurse-led (advanced practice nurse) intervention.
- Study published between 2011–2021.
- Discussion of head and neck cancers (including oropharyngeal cancer).

Exclusion criteria

- Case study reports of patient experience without nursing intervention.
- Use of multidisciplinary team INCLUDING advanced practice nurse.
- Focus not on head and neck cancers.
- Outcome focusing on nurse/clinician experience rather than patient experience.

Search outcomes

A primary search of databases (MEDLINE, Scopus, PsychINFO, Cochrane and CINAHL) yielded 134 results. From this, 22 duplicate records were removed, and 22 records were marked as ineligible by automation tools. The two authors screened for inclusion using the Covidence website. Initial records were excluded using the abstract and then further full text screening identified the final studies.

Data abstraction

The data was downloaded from the studies and saved in an excel spread sheet under the following headings: title, author (year), country, study design, sample and variables reviewed. The Pickering framework was used to complete the review process. Data from the studies were converted into categorical domains and studies were graded as 0 or 1 to provide binary data of the study aspects.

Quality appraisal

The selected studies were appraised using the Mixed Methods Appraisal Tool (MMAT) to identify strength of the research process[29]. The MMAT approach gives studies a numerical score from 1–5 based on the category of study methodology.

Results

Overview of literature

Of the 13 articles[30-42] included for analysis, seven were cohort studies, four were observation-based and five were randomised control trials. The analysis identified that 12 of the nurse-led clinics were outpatients, and four were based on the generalised role of an advanced practice nurse. Geographically, only one study was based in Australia, with the majority based in either Europe (7) or the USA (8). Key findings obtained from each study are highlighted in Table 1. When identifying the age of participants, only eight studies detailed specifics with an overall mean age of 62.48 years. Sample sizes ranged from 1–449. Not all studies included the length of the study; however, the average was 9.7 months (n=10) with study lengths ranging from 4 months to 4 years.

Quality appraisal

All studies were appraised using the MMAT[29]. For the six studies classified as qualitative, the MMAT critique reflected a large variation in quality; interpretation of results and coherence between data sources was identified as a key domain that was not met during quality appraisal. When critiquing the two randomised control trial studies, the main areas of concern related to the domains of assessor blinding, and adherence to protocols. The main area of concern for the five non-randomised studies was that of adjustment for confounding factors. Lastly, for the mixed-methods study, appraisal found inconsistencies

Table 1. Summary of studies included for systematic review

Title	Study design and length	Mean age / sample size	Clinic structure	Data collection	Key findings
Balusik (2014)[30] • USA					
Management of dysphagia in patients with head and neck cancer	Case study	Mean = 65 years (n=1)	Advanced practice nurse 1:1 tailored care	Interviews (quality of life)	This case study explores a single patient experience with an advanced practice nurse. In this situation, the nurse made referrals to appropriate multidisciplinary team members, including speech therapy, dietetics and physiotherapy.
Collie et al. (2014)[31] • Canada					
Qualitative evaluation of care plans for Canadian breast and head and neck cancer survivors	Descriptive qualitative	Mean = 55 years (n=21)	Survivorship education 2 weeks after treatment completed	Personal interviews, measurement of experience of education (quality of life)	Evaluation of survivorship care plans. Patients reported positive emotional impacts from the care plans but expressed concern about communicating this information to physicians.
da Silva Martins et al. (2018)[32] • Netherlands					
Nursing consultation in the head and neck cancer radiotherapy: a cost-health utility relationship analysis	Mixed method (5 months)	Mean = 64 years (n=10)	Nurse-led consultation and assessment for referral to multidisciplinary team	University of Washington Quality of Life questionnaire (UW-QOL)	Utilisation of a nurse-led follow up clinic was helpful in enhancing quality of life. It was found that greater utilisation occurred when adverse events occurred to patients within the study.
de Leeuw et al. (2013)[33] • Netherlands					
Nurse-led follow-up care for head and neck cancer patients: a quasi-experimental prospective trial	Quasi-experimental (12 months)	Mean = 59 years (n=160)	Six 30-minute consultations bimonthly 12 months after treatment. Physical and psychological screening and educational advice	Health-related Quality of Life questionnaire (HR-QOL) at 6 and 12 months	By comparing to conventional physician-led follow up, it was found that nurse-led follow up for head and neck cancers resulted in greater improvement in health-related quality of life.

Title	Study design and length	Mean age / sample size	Clinic structure	Data collection	Key findings
de Leeuw et al. (2014)[34] • Netherlands					
Nurse-patient communication in follow-up consultations after head and neck cancer treatment	Descriptive qualitative (7 months)	Patients and partners mean = 58 years (n=10)	Six 30-minute consultations bimonthly 12 months after treatment. Physical and psychological screening and educational advice	Observational videos of clinic visits analysed for nurses' ability to identify patient and family cues, enabling assessment and tailored information	Evaluation of communication methods used between nurse and patient during follow-up visits for head and neck cancer. It was found that adequate response to patient concerns was observed through emotional cues and distancing behaviours.
Duman-Lubberding et al. (2017)[35] • Netherlands					
Durable usage of patient-reported outcome measures in clinical practice to monitor health-related quality of life in head and neck cancer patients	Mixed methods (6 months)	Mean = 63 years (n=449)	Nurse-led consultations (mean time 10 minutes to discuss patient concerns)	Health-related Quality of Life questionnaire (HR-QOL)	Nursing consultation topics and use of service. Topics discussed were symptom management and anxiety, and that patients valued the nurses' time, knowledge and listening skills.
Ohlstein et al. (2015)[36] • USA					
Initial experience of a patient navigational model for head and neck cancer	Retrospective observational (4 years)	Mean = 63 years (n=93)	Nurse navigator consultation to establish care within 2 days after diagnosis	Time from diagnosis to treatment initiation	A patient-centric navigation program was formed where a nurse reviews a patient following diagnosis and arranges to schedule additional tests and biopsies if needed. Following this review, all results are collated and presented to a multidisciplinary team for review and treatment recommendations.
Spellman, Kanatas & Ong (2018)[37] • England					
Early experience of a nurse-led clinic in a tertiary centre	Case report (time unknown)	Mean unknown (n=104)	Nurse-led consultations with organisation of appropriate referrals	Suitability for nurse-led clinic	Determined the suitability of a nurse-led clinic for 'fast-track' referral. This study determined that 62% of patients would be suitable for this intervention.
Terzo et al. (2017)[38] • USA					
Reducing unplanned admissions	Observational (12 months)	Mean = 59 years (n=97)	Weekly symptom management clinic	Rate of visits or unplanned admissions to hospital/emergency department. Compliance with treatment	Implementation of a nurse-led symptom clinic for head and neck cancers treated with radiotherapy resulted in a marginal reduction of unplanned hospital and emergency department presentations.
Turner et al. (2019)[39] • Australia					
The ENCHANCES study: a randomised control trial of nurse-led survivorship intervention for patients treated for head and neck cancer	Randomised control trial (6 months)	Mean = 60 years (n=109)	Nurse consultation with patients in face-to-face interview (up to 60 minutes) to develop individualised care plan	Health-related Quality of Life questionnaire (HR-QOL) Hospital Anxiety and Depression Scale (HADS) Functional Assessment of Cancer Therapy Head and Neck (FACT-H&N)	Nurse-led intervention of cancer survivorship plan was insufficient to improve overall quality of life compared to usual care.
van der Meullen et al. (2013)[40] • Netherlands					
1-year effect of a nurse-led psychosocial intervention on depressive symptoms in patients with head and neck cancer	Randomised control trial (1 year)	Mean = 60.4 years (n=205)	Nurse-led counseling sessions using manual assessment and tailored information with six 60-minute sessions for each patient	EORTC QOL-H&N37 Centre for Epidemiologic Studies-Depression (CES-D)	Nurse-led psychosocial intervention for depressive symptoms resulted in greater improvement of emotional functioning compared to usual care group – 40% completion of all sessions.

Title	Study design and length	Mean age / sample size	Clinic structure	Data collection	Key findings
Wells et al. (2008)[41] • Scotland					
A study to evaluate nurse-led on-treatment review for patients undergoing radiotherapy for head and neck cancer	Mixed methods observational (7 months)	Mean = 64 years (n=20)	Nurse-led review using check list. Personal follow-up and management of complications	EORTC QOL-C30 EORTC QOL-H&N37	When compared to traditional physician-led follow-up, nurse-led follow-up resulted in improved nutritional and oral management. However, emotional functioning was greater in the physician-led follow-up group.
Westman et al. (2019)[42] • Sweden					
Patient-reported perceptions of care after the introduction of a new advanced nursing role in Sweden	Cross-sectional cohort (2 years)	70% >65 years (n=395)	Clinical nurse consultant assisted with transition between services and access to information on-call	EORTC QOL-C30 EORTC QOL-H&N37	Introduction of advanced cancer nurse role resulted in patient-reported improvements in access to care, information needs and individualised care plans.

between qualitative and quantitative results and issues relating to coherence for each methodology utilised.

Variables measured

Most studies focused on the quality of life from the patient perspective (n=13). The other areas of participant evaluation focused on the patients' perspective of function assessment (n=4), mood and emotional functioning (n=4), health information needs (n=3) and access to care (n=3). Finally, two studies focused on the amount of hospital re-admissions, and one study focused on patients' overall satisfaction with the clinic.

Measurement of variables

There was a range of variables used to measure quality of life. Of these, the most common were the validated scales Health-related Quality of Life questionnaire (HR-QOL) and the EORTC QOL-H&N37. The standard HR-QOL is also known as the RAND-36 and measures individual responses across the domains of physical functioning, role limitations caused by physical health problems, role limitations caused by emotional problems, social functioning, emotional well-being, energy/fatigue, pain and general health perceptions[43] The EORTC QOL-H&N37 is a scale specific to head and neck cancers and is often used to measure the effect of psychological interventions[44]. Overall, the questionaires used within each article reviewed were standardised and appropriate. However, since there were different measurements used for each study, a meta-analysis of the combined effect of nurse-led clinics for head and neck cancer patients is unable to be performed.

Patient outcomes

Some of the studies included in this review directly compared conventional physician-led follow-up to nurse-led follow-up for head and neck cancers[33,41], while others focused on the nurse-led component without comparison[30,32,35,37,38,40]. When exploring the domain of an advanced practice nurse[36], it was found that this intervention improved patient-reported access to care and information needs[42]. Furthermore, another study focused on the communication used during nursing consultations, and found an adequate response to patient concerns was observed through emotional cues and distancing behaviors[34]. Other studies focused on the implementation of survivorship care plans[31,39]; however, it was reported that this implementation alone was insufficient to improve overall quality of life[39].

Discussion

The analysis of the studies highlighted a range of both the quality and variables explored. The mean age of combined participants included for this review (63 years old) reflects the higher end of the average age of diagnosis for head and neck cancers between 50–64 years[45]. The current review highlighted that there has been a lack of clinical research to substantiate the benefits and barriers of nurse-led clinics. However, as delivery of care in cancer has changed, there has not been significant research to identify the changes to patient care outcomes[46]. The participant numbers in the reviewed studies reduced the ability to critique the ability of nurse-led clinics to be generalised and used in different geographic areas and cultural diversities[47]. The recruitment and sample information were not clearly presented in included studies; however, all except one study recruited participants from a pool of clinic patients. Recruitment via clinic participation is helpful for studies as the patient demographic is known and information that may be required to study is often already present within the clinic database. However, it does reduce the ability to translate the findings to other geographic areas and cultural differences[48].

The primary focus in the studies was measuring the changes in quality of life from the patient perspective. Overall, most studies reported an increase in patient-reported quality of life with the intervention of a nurse-led consultation. This supports the previous findings in which nurse-led clinics redirect the focus of consultation to a patient-centered focus rather than the traditional treatment-focused approach[18–20]. One theory of why nurse-led clinics increase quality of life is that nurses are well prepared at identifying signs and symptoms of distress and being able to provide coordinated holistic care to improve symptom management and satisfy information needs[9]. Within this review, a similar response is reflected in the study by de Leeuw et al. which reports that during nurse-led consultation, adequate response to patient concerns was observed through emotional cues and distancing behaviors. Further reviews in general nurse-led oncology management suggest that improvements in quality of life are attributable to comprehensive care, psychological and/or social support, health information and individualised consultation[49].

Emphasis on patient satisfaction

In the area of oncology care, patient satisfaction is shown to be an important contributing factor to the overall improvement in quality of life[50]. It has been suggested that patient satisfaction levels can affect health-related behaviours, compliance with treatment, and motivation to seek care, all of which in turn can aid to increased quality of life[50]. One study by Loiselle et al. examined the domain of emotional support with the context of nurse-led models of care in general oncology patients. It was hypothesised that nurses provide enhanced emotional support by encouraging patients to express their emotions while simultaneously addressing these patient concerns[51].

Context within the Australian environment

As outlined in the Australian Cancer Council *Optimal care pathway for people with head and neck cancer guidelines,* ongoing access to specialist nursing "is important for managing the physical, psychological, and social/practical needs that may arise with head and neck cancer treatment"[52]. Currently in Australia, there are few services that offer highly specialised head and neck cancer care. In Victoria, the Peter Mac Cancer Service offers nurse coordination services for both medical/radiation and surgical head and neck oncology[53]. In New South Wales, the Chris O'Brien Lifehouse operates a nurse-led rapid access assessment clinic, alongside many other consultant-led and multidisciplinary-led teams[54]. These are a few select examples of successful nurse-led services operating in the current Australian environment.

Limitations

The inclusion/exclusion criteria for this review allowed for studies which had nurse-led clinics in the outpatient setting and those within the hospital and inpatient contexts. It is important to note that while these both utilise the services of an advanced practice nursing role, the overall aims of the service were different. Often with an inpatient service, the main goal is to facilitate a smooth and efficient admission that ends with discharge, whereas the directive in outpatient settings is often an ongoing and flexible process. However, by considering the aspects of these services that contribute to success, the key indicator of patient quality of life is of the upmost importance, regardless of the setting. Further research may be considered by further refining inclusion and exclusion criteria to focus only on outpatient services. However, this may result in less literature available for review.

Conclusion

Nurse-led clinics to support and follow-up persons with head and neck cancer allow for person-centred care. The current studies highlighted the benefits of nurse-led clinics to improve the quality of life of persons with head and neck cancer. All, 13 studies showed an increase in patient-reported quality of life. It has been hypothesised that nurse-led clinics achieved this increased quality of life by redirecting the focus of consultation to the current and specific requirements from a patient-centred focus. These findings may have importance regarding future policy developments, including further implementation of similar clinics in areas without such a service. However, further research may be required to study the financial and resource availability for the utilisation of nurse-led clinics in the future.

Conflict of interest

The authors declare no conflicts of interest.

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