

Partners in Care co-design case study

Post-treatment support for women with cervical cancer

Women's Health, Canterbury District Health Board

Context

Over the past five years the gynaecologic oncology service within the Canterbury District Health Board (DHB) has provided diagnostic and treatment support for approximately 80 women with a diagnosis of cervical cancer. The service has delivered care and follow-up services for women within the Canterbury area and from all other DHBs within the South Island. Treatment for cervical cancer can involve surgery, chemotherapy and radiation with single or combination therapy. As the specialist nursing team, we wanted to examine the experience of this group of women and to listen and respond to their identified needs. We made the decision to focus initially on the women within this group who had undergone combination treatment.

Aim

Our aim was to work in partnership with women who have recently undergone combination (chemotherapy and radiation) treatment for cervical cancer to explore their experience and support needs beyond the completion of their treatment. We want to better understand the consumer experience and gather consumers' ideas of what currently works well and what could be improved through the use of a co-design approach.

Start up

Women who receive treatment for cervical cancer experience a range of physical and psychological post-treatment effects that can potentially last for an extended period beyond the completion of their treatment (Campbell et al 2019). In line with international literature suggesting more work is needed to identify, anticipate and manage ongoing effects of cervical cancer treatment (Campbell et al 2019), the gynae oncology nursing team recognised the complexity of physical and psychological needs of this group. The team wanted to determine how best to provide patient-focused follow-up care.

As Christchurch women's and public hospitals are tertiary referral centres and cover a large geographical area, for the purposes of this project we focused on those women who were receiving follow-up care after combination treatment for cervical cancer who lived within the Canterbury DHB catchment area.

We worked with a kaiāwhina (advocate) for wāhine Māori (Māori women) in Christchurch Women's Hospital to ensure that we are engaged with wāhine Māori and that they have a strong voice in the feedback we received. We also consulted with Te Komiti Whakarite, a committee who assesses

and provides cultural advice to Canterbury DHB. The following letter is Te Komiti Whakarite's response to our request for feedback.

Research title: Improving post-treatment support for women who have had cervical cancer

Tēnā koe Sue,

Ka nui te mihi tēnei ki a koe me tōu rōpū o ngā Kairapukorero ki te hāpai ō te kaupapa whakahirahira mōu, mōku mō tātou katoa. Ko Rapunga Kōrero te mea nui. Nō reira tēnā koe me te rōpū o ngā Kairangahau, tēnā koutou katoa.

The translation of the sentence above is: Greetings to you and your group in raising this subject of great importance. The presentation and rationale is recognised as important. Our group wishes you well.

Thank you for submitting the above research proposal to Te Komiti Whakarite, the Canterbury DHB Māori health research committee for Māori consultation.

We have read your proposal, which is well considered and clear about how the researcher will take participants' cultural needs into account. We are happy to offer our support regarding any further culturally responsive practice and guidance you may seek advice on.

Ultimately this type of research has the potential to reduce the health disparities between Māori and non-Māori.

We wish you every success in your research and the Komiti would appreciate a summary of your findings on completion of the current project. Te Komiti Whakarite would be willing to assist in the dissemination of your findings to the appropriate Māori organisations, Māori health professionals and Māori researchers.

I hope this letter will suffice in terms of the application. Please contact me should you need any other information that may not have been included in the letter relevant to your research.

Heoi anō (be strong and see you again)

Eru Waiti

Chairperson

Te Komiti Whakarite

We also prepared a submission to the Regional Cancer Service Quality Improvement and Research Governance Group to get their input/approval around ethical considerations for the project. An application for ethics review for low-risk research within the Canterbury DHB Department of Oncology was submitted on 3 December 2019, and approved.

Engage

Our project team were in contact regularly throughout the project via face-to-face meetings and phone calls/emails.

As a project team, we discussed options for capturing experiences and agreed to hold a consumer-led focus group meeting to listen to women's experiences and identify ideas for improvement. Ten women were invited to attend a focus group meeting to explore their treatment and post-treatment experience.

To engage people within this project, we developed two elevator pitches: one for staff (Figure 1) to provide information about the project, and one for consumers (Figure 2) that also provided details about what we were aiming to achieve and how they can contribute to it. Consumers were initially sent a letter inviting them to attend the focus group meeting (Appendix 1), which was followed up two weeks later with a phone call.

Figure 1: Elevator pitch for senior leaders/staff

Kia ora,
My name is Sue Morel.

I am the project lead for work that is exploring the patient's experience after combination treatment for cervical cancer. The Southern Cancer Network and the Health Quality & Safety Commission are both supporting work like this throughout New Zealand.

International literature suggests more work is needed to anticipate and manage potential long-term and late effects of diagnosis and treatment, and at the moment we currently have only limited clinical reviews but no specific consumer-led follow-up programme.

We are inviting women who have received combination treatment for cervical cancer to tell us about their experiences and particularly about what support they feel was needed during and after their treatment.

Our goal is to better understand the consumer experience and gather their ideas of what currently works well and where we need improvement.

Figure 2: Elevator pitch for consumers

Kia ora,
My name is Sue Morel.

I am the project lead for work that is exploring the patient's experience after combination treatment for cervical cancer. The Southern Cancer Network and the Health Quality & Safety Commission are both supporting work like this throughout New Zealand.

We are bringing together nurses and consumers like you to explore the experience of treatment for cervical cancer.

The project team currently has two women who are giving us advice, and we are inviting other women who have received combination treatment for cervical cancer to tell us about their experiences and particularly about what support you feel was needed during and after the treatment.

We would like to have a consumer-led focus group meeting where we ask some questions and listen to the experiences of what works well, where we need to improve, and ideas of what other forms of support could be made available. We would really appreciate if you would consider being part of this focus group.

Capture

Seven of ten identified consumers (two of whom identified as Māori) participated in the focus group meeting. This was held at an educational facility as opposed to a clinical setting because we felt that this would be a more comfortable environment. In addition to the consumers, the focus group meeting was also attended by the project lead, three registered nurses and the kaiāwhina for wāhine Māori in Christchurch Women's Hospital.

On arrival the participants were provided with a welcome leaflet (Figure 3) and the questions we planned to explore with them. They were asked to sign a consent form for us to use unidentified information generated within the session and that they agreed to maintain confidentiality regarding the discussion so all women could feel able to share their experiences. The women were also given the opportunity to provide their email addresses for further contact if they wished.

Figure 3: Content of the welcome leaflet

“Good evening and welcome to our session. My name is Sue Morel and assisting me is Tash Chisholm, Anjina Kumar and Susan Taylor. We all work for Canterbury DHB. We have been working alongside **** and ***, who are women who have gone through a similar journey to you all. Thanks for taking the time to join us to talk about your experience of treatment for cervical cancer and particularly about what support you feel was needed during and after your treatment.

Our goal is to better understand your experience during and after treatment by listening to your experiences of what works well, where we need to improve, and ideas of what other forms of support could be made available.

We have a few questions that we will use during the evening. There are no wrong answers but rather differing points of view. Please feel free to share your point of view even if it differs from what others have said. Keep in mind that we are just as interested in negative comments as positive comments and that at times the negative comments are the most helpful.

You may be assured of complete confidentiality. We will be making notes of the discussion, and Tash and I will collate the responses you provide tonight; however, we won't be using any names in our feedback. The feedback will be used to provide support for improvements within the service we currently deliver to women receiving treatment for cervical cancer.”

After introductions and karakia, the following questions (Figure 4) were used to guide the conversation.

Figure 4: Questions used to guide the focus group meeting

1. Thinking back to when you received treatment, what went well?
2. What didn't go well during treatment?

3. What would have made treatment better?

The next few questions focus on the recovery period after treatment.

4. Can you tell us about the information you had? Were you able to read through it? What was helpful about it? In hindsight, what did you need that was not there?
5. What other support would you have found useful or would have helped you in your recovery after treatment?
6. What difficulties did you have in getting followed up after your treatment?
7. If we could make one change that would make treatment and recovery better, what would that be?
8. Have we missed anything? Is there anything further anyone wishes to add before we finish up?

Information and data were collected by two scribes, and themes were written on a white board in the room for all to see and refer to during the focus group meeting. Participants were also provided Post-it notes to use if they did not feel confident/comfortable sharing in the wider forum. This was a particularly effective mechanism for at least one participant to share her experiences, which could have otherwise been missed.

The project team was pleasantly overwhelmed with the number of participants who joined the focus group and how they so willingly shared their experiences. The conversation and information sharing flowed freely, with the focus group meeting going well over its allocated time.

Understand

The project team reviewed and collated the information from the focus group meeting and identified seven themes and a range of ideas. These were emailed to participants requesting them to confirm the accuracy of the project team's data interpretation and inviting them to correct or add further if they wished.

1. The volume of information

Women felt that the volume of information that was provided to them was overwhelming, daunting and difficult to retain. They suggested that it would have been much better if more individualised information was provided in relation to where they were within a timeline. Consistency of the information is important, as is the provision of time to revisit information during the treatment process.

2. Learning from others

While the range of information provided was considered helpful, overall it did not fully meet the women's needs, and they said that they would like to have the opportunity to discuss treatment with a woman that has gone through the same experience. They felt that they could learn a lot about coping mechanisms for everyday life, as this type of knowledge was not really included in the information provided through clinical services.

3. Future fertility

There was wide discussion about understanding what options there are regarding ongoing fertility. The consensus was that while moving from diagnosis to treatment quickly was optimal clinically, women need more time to explore and proceed with fertility options before treatment actually started, and those options were no longer available.

4. Nursing support

Nursing support was highly regarded, especially having one point of contact if the women had questions or were unwell. However, many in the group felt that they did not have enough access to nursing or one person to contact throughout the time of their cancer diagnosis and treatment.

5. Psychological therapy

While some women can remember being offered psychological therapy, some said they had declined it because they did not realise they needed it, or they did not fully understand the benefits, or were worried that it might carry a stigma if friends, family or their workplace found out. Once they had declined the therapy, it was not offered again. Women suggested that psychological therapy could be better explained and that it should be offered at multiple points during and after treatment, even if it was declined initially. This is one area that discussion with other women who have had therapy (as indicated in theme 2) could be helpful.

6. Side effects

Consensus from the group was that information about going through menopause, ongoing bowel symptoms and diet, and maintaining pelvic health, including dilator use, needs to be consistent and revisited often with the support of a dietician/nutritionist, doctors, nurses, a pelvic health physiotherapist and a sex therapist. This was also a time when counselling support focusing on relationships and intimacy would be helpful.

7. Tikanga Māori

Tikanga Māori was identified as important in supporting cultural safety at all points during the journey. Māori participants spoke about the need to build a relationship and understand their culture, custom spirituality, and the importance of etiquette and whānau in their lives. To enable this, we need to provide consistent support for wāhine Māori with input from specialist health workers.

There were some specific insights that we felt were particularly important (Figure 5).

Figure 5: Insights from women who participated in the focus group



Improve

Having identified key themes and ideas that had come from the capture phase of the project, the project team of nurses and consumers planned to hold an information-sharing session with the focus group participants on the topic of menopause as a result of treatment.

The majority (5/7) of the women who had experienced premature menopause as a result of their treatment felt that they had not received accurate and timely information about this. They highlighted that the timing of getting the information could have been better. Also, details about the symptoms they may experience and the treatment options were not clear. They felt that the specific information about menopause got lost in the sheer volume of reading and verbal instruction that they got as part of their treatment plan.

From this planned session the hope had been to develop a draft resource that we then could have measured. However, due to the circumstances of the global COVID-19 pandemic, a meeting was impossible and the decision was made for the project team to email the group with existing resource material from the Australian Menopause Society and Health Navigator New Zealand.

The resource was sent to the seven participants of the initial focus group along with a short survey (Figure 6) asking for their comments and any further ideas that would make the information helpful and appropriate. This information was also sent to the kaiāwhina for wāhine Māori for comment.

Figure 6: Survey seeking feedback on the draft information on menopause

Menopause information

Please let us help women who have completed chemo/radiation for cervical cancer. We are interested in your honest opinion. This questionnaire is anonymous and confidential.

Please circle the number or word that best applies

1. What do you think of the draft information sheets?

1	2	3	4	5
Excellent	Good	Average	Poor	Very poor

2. How easy is the language used to understand the information?

1	2	3	4	5
Not at all easy to understand	A little easy	Somewhat easy	Easy	Very easy to understand

3. What do you think of the way the information is presented?

1	2	3	4	5
Excellent	Good	Average	Poor	Very poor

4. The amount of information is:

1	2	3
Too little	Enough	Too much

5. Is there any information you would like to be added?

Suggestions

6. Is there anything you think is not needed and could be removed?

Suggestions

Please let us know if you have other comments or suggestions here.

Results

Responses were received from 57 percent (4/7) of the women who attended the focus group meeting in the form of a completed survey with additional suggestions.

Five women in the group identified themselves as pre-menopausal at the time they started their treatment. Four of them completed the survey and sent suggestions. The following results are from this group because the two women who were post-menopausal didn't reply.

- Q1 – One woman (25 percent) rated the information as 'Excellent', two women (50 percent) rated it as 'Good', and one (25 percent) rated it as 'Average'.
- Q2 – All four women said that the language was easy to understand.
- Q3 – All four women felt the way the information was presented was good.
- Q4 – Three of the four women (75 percent) said the information was enough, and one woman (25 percent) said it was too little.
- All four women suggested that the draft information still needed to be more specific to menopause as a result of chemo radiation as well as talking through the risks and benefits of hormone replacement therapy. They felt that a face-to-face discussion specifically about this would be helpful but there was no consensus about when the best time for that discussion would have been.

Next steps

1. Share the learning with other key stakeholders who support women on the cervical cancer journey.
2. Continue to work with women to further develop the resource on menopause for women undergoing the treatment modality of concurrent chemotherapy and radiation.
3. Review all other patient information available that is provided by both gynaecology and oncology services with the intent of developing an individualised care plan for each patient, including a treatment timeline/pathway.
4. Create a pathway to refer women for counselling support for all patients prior to treatment.
5. Identify women who have completed treatment who would be willing to have contact with new patients.

Working as a co-design team

Sue Morel reflects:

It has been both rewarding and challenging. We feel privileged at being trusted with the personal experiences of the women involved. We believe we have a responsibility to apply what we have learnt with respect and achieve as much as possible to better the treatment journey of these women.

Co-design gave us the opportunity to engage with them and a structure by which we could record their opinions and suggestions.

As a consumer-focused project, our hope is that we can effect change as we can show evidence that it is what the consumer wants and needs.

If I was to look at another project, I would want to have a bigger team and more identified roles now that I understand what is required. A team member who was skilled at engaging with stakeholders would be invaluable. However, I believe it should not be too structured as this may lead to the loss of the individualised focus of the project.

Consumer 1 reflects:

It was great to have the opportunity to put into action things that I had been thinking about from diagnosis and during my treatment.

I enjoyed working alongside the hospital team and not in a patient role.

I felt I had a voice and was listened to.

The focus group helped me connect with other women who felt the same, and it reassured me that they had the same experiences as me.

Consumer 2 reflects:

Being involved in the co-design project as a consumer has been extremely rewarding. I have thoroughly enjoyed contributing to this process by sharing my experience to help identify areas that worked well or that may need improvement. Not only are we able to influence change that may help women during their treatment, but I have also met women who have received the same or similar treatment. Having the ability to chat with someone who fully understands your journey and struggles is priceless. Thank you so much for including me in this initiative. I would be happy to do this again.

Project team

Name	Role	Email	Organisation
Sue Morel	Clinical Nurse Specialist	susan.morel@cdhb.health.nz	Canterbury DHB
Tash Chisholm	Clinical Nurse Specialist	natasha.chisholm@cdhb.health.nz	Canterbury DHB
Consumer 1	Consumer	Details confidential	
Consumer 2	Consumer	Details confidential	

Reference

Campbell G, Thomas TH, Hand L, et al. 2019. Caring for survivors of gynaecologic cancer: assessment and management of long-term and late effects. *Seminars in Oncology Nursing* 35(2): 192–201. <https://doi.org/10.1016/j.soncn.2019.02.006>

Appendix 1: Letter to consumers inviting them to a focus group meeting

20/1/20

Dear,

With support from the Southern Cancer Network, Health Quality & Safety Commission and kaiāwhina for wāhine Māori, the gynae oncology service at Christchurch Women's Hospital is undertaking a co-design project that is exploring patient experiences after completion of combination treatment for cervical cancer.

Together with the senior nursing team of Sue Morel (gynae), Tash Chisholm (oncology) and two women who have had similar treatments to yourself, we want to bring together a focus group of nurses and consumers like yourself to explore areas where post-treatment care and support could be improved.

Questions and ideas are encouraged. Our aim is to identify common themes and ideas that may result in service improvements.

Details of when (tentatively Tuesday 18/02/2020) and where will be communicated to you when we have a clearer picture of what works best for those who want to attend. We would hope the group meeting would not last longer than 90 minutes.

If you are unable to attend but still want to share your thoughts and ideas, we will have other options available.

We will be calling a couple of weeks after you have received this letter to answer any questions you may have about the process.

Please share with us any thoughts or suggestions about this project.

All information shared by you will be confidential, and your participation or not will not affect in any way the treatment or support you receive.

Warm regards,

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Tash Chisholm, Radiation Oncology CNS, natasha.chisholm@cdhb.health.co.nz