

International Online Breast Cancer Rehabilitation Summit 2016 -for health professionals

Presenter: Lou James

I am passionate about helping people live as fully and actively as possible after a cancer diagnosis. As a cancer rehabilitation physiotherapist, I have seen first hand the physical and emotional affects cancer treatments and the disease itself can have on the lives of people affected and the those close to them.

I am now fortunate to work with a growing network of Pinc & Steel Cancer Rehabilitation Physiotherapists who are really making an impact on the lives of thousands of patients each year. The rehabilitation needs of women undergoing breast cancer treatment and beyond are now being documented more in the research. I have just been to the Clinical Oncology Society of Australia Conference on the Gold Coast. The conference this year was combined with the Australia New Zealand Breast Cancer Clinical Trials Group conference so there was a huge smorgasbord of fascinating and really relevant research on offer. The evidence for the benefits of rehabilitation and exercise is very encouraging and I think we need to **work together as health professionals** in this area of care to extend the scope of our care to support more people in need. One of the things I have learnt working in this field and teaching physiotherapists is that people need support through **many** stages of their **treatment and recovery**, and to **cope with the ongoing challenges of life** after cancer treatment.

It is **not enough** to just address the scar or range of motion issue -- we need to look at the wellbeing of the whole patient and make sure we are

helping them to **reach their potential** to live as actively and fully as possible.

I am going to talk today about extending the scope of physiotherapy care to reduce the burden of cancer for our patients and show you evaluation data from two examples of programmes that do that.

Like many of the other presenters on this International breast cancer summit have mentioned - Cancer patients are at risk of experiencing adverse physical and psychosocial consequences of their cancer and it's treatment. With an increasing number of patients treated for and living with cancer, these consequences can leave a grueling physical and mental legacy for many years. This can wreak havoc with people's body confidence, strength, stamina and their life plans, the absence of children, the ability to work full time and achieve other life goals. As Julia Rowland has said – being disease free – does not necessarily mean being free of your disease. –Cancer is a chronic disease, people are either living with cancer or Living with the side effects of cancer.

This slide shows a list of the chronic sequelae of cancer.

In order to support patients in the most optimal way during and after cancer treatment it is important to understand that: Compared with people who have not had cancer, **cancer survivors** have an increased lifetime risk of developing:

- New primary cancers
- Cardiovascular disease
- Diabetes
- Osteoporosis

- Functional decline and
- Cancer recurrence
- And that it's impact is far reaching with social, financial and vocational implications as well

Deconditioning is one of the most prevalent cancer related treatment complications. The musculoskeletal, respiratory and cardiovascular systems are all affected by cancer-related deconditioning and can cause serious complications if not managed. It doesn't take long for the cycle of deconditioning with physical inactivity from breast cancer treatments to lead to further inactivity and increase the potential for disability.

Cancer rehabilitation physiotherapists are in a perfect position to give exercise counseling to increase physical activity and optimise physical functioning for women with breast cancer. Unfortunately, many people miss out on this care because if women don't have any surgical complications or lymphoedema etc they are often not deemed high rehab needs by the hospital system and miss out on referral. .

Deconditioning can lead to a negative spiral for women's mental health after breast cancer as well, including decreased sense of wellbeing, a sense of helplessness, and they are less likely to ask for help and connect with exercise programmes in the community.

It can not be stressed enough how important physical activity is to cancer patients. It needs to be understood that while surviving cancer itself is a difficult journey, suffering from additional complications related

to inactivity can make recovery more difficult, can affect cancer survival itself and can lead to serious lifelong complications.

This slide show's PINC and STEEL Tiered Programme of Appropriate Care

This approach to rehab is a tiered approach designed to work with a patient from **early stages through to well-recovered**. This tiered approach also supports cancer patients who come to rehab some time after their initial intervention.

Individual programming is very important initially for women with breast cancer but the recommended and partially funded series of 5 or 10 sessions typically needs to flow into further supportive programming. The next tier of interventions is small group exercise programmes and PINC and Steel have developed a stand up paddle board programme and a pilates/yoga & cardio programme called. Next Steps. After completion of one or both of these programmes women are encouraged to get involved in community events.

We see examples of women with breast cancer going through this tiered programme and then joining our move over cancer fundraising events to support others with cancer newly diagnosed. It is so rewarding to be involved in all phases of the programme, to see women getting back to doing the things they love and helping others that come after them. Our Pinc & Steel cancer rehabilitation programmes are individualised physiotherapy programmes but today I want to talk to you more about Tier 2 – and how physiotherapists can extend their support in the group exercise setting.

So what is the Next Steps Program. It was designed following discussion with NZ Breast Cancer Foundation who were looking for a nationwide exercise programme to support women after Breast Cancer. It is a combination of pilates, yoga and cardio exercises using a step up so we could cater for different levels within the group setting. We also included a 'Word of the Week'. Which were concepts taken from Positive Psychology programmes for wellbeing, so the women were given a word such as 'Gratitude' or 'Energise' and encouraged to spend time each day completing an activity that would support their sense of wellbeing. Physiotherapists trained in oncology rehab were selected to be trained to pilot the 10 week programme from their clinics. It was important to know whether the programme was going to meet its aims of supporting health and fitness and wellbeing goals and to see if it was actually feasible – that is would it be an attractive rehab option

11 physio clinics took part and 87 women with Breast Cancer completed both surveys. (the remaining women had other types of cancer but the data I'll present today is just on the women with breast cancer. The mean age was 55 and over 70% attended 8 – 10 sessions. This slide shows the range of treatments represented in the group we saw.

Participant response was extremely positive with 94% saying they loved the whole course and almost all of them saying that they would recommend it to a friend. 80% said that it made them more interested in getting fit.

The results for wellbeing indicators were dramatic with a large decrease in those reporting problems with fatigue, body confidence and general confidence. There were less spectacular but still significant reductions in reports of feeling down and sleep difficulties. Serious fatigue problems reduced from 63% to 23% The feeling of being less confident about my body reduced from 55% to 21%

Using questions from the QLQ30 we investigated aspects of daily functioning and as you can see these measures showed a general trend of decreases. Strongly indicated responses – a reported ‘very much so’ decreased significantly for limitations in leisure activities, the feeling tired and weak and the need to rest. But what I really want to draw your attention to in these results are firstly the significant reductions in reported feeling tense, worried and irritable – these affective aspects of wellbeing are likely to have a really profound effect on how you feel about life the universe and everything. So these results were really interesting. However, the biggest change on all of the measures we assessed was this one – memory difficulties went from a 38% reporting that they were very much a problem to 12.5% - a 2 3rds reduction.

So in summary then, participants really enjoyed the programme. They reported overall improved health and wellbeing, and improved specific measures of health and fitness. The biggest reported changes were in reduction in reported memory and fatigue problems but confidence, body confidence and ‘sometimes feeling down’, anxiety, worry and irritability all showed significant decreased.

Many of the women are still exercising and have joined tier3 activities and NZBCF is now funding this programme nationwide for BC patients.

We have now trained more physiotherapists to run this programme in their clinics and I've been overwhelmed with their positive responses about taking the class and many have told me how they have seen health benefits themselves.

I am now going to present evaluation data gathered from a pilot standup paddle boarding programme developed to meet the exercise needs for breast cancer patients following their initial surgery and treatment. Participants were screened by a Pinc cancer rehab physiotherapist prior to enrolment to ensure that they were well and strong enough, with adequate balance.

The PaddleOn programme is divided into eight modules, each with a specific rehabilitation and learning focus: balance and posture, shoulder and thoracic flexibility, core stability, shoulder strengthening and stability, arm strength and turnover, dynamic balance and turns and cardiovascular fitness and endurance.

The pilot programme was run in 7 different groups, with a maximum group size of 10 participants. These groups used four different locations which were chosen because of calm water with no significant currents.

Fig 1: Positive changes were noted in the series of questions relating specifically to the benefits anticipated from the PaddleOn programme and prompted by the question "Thinking about my health now, I would like...", with percentages decreasing (indicating improvement) with respect to feeling stronger, improving balance, spending more time

outside, being able to feel more relaxed and receiving more support from people who understand breast cancer

Improvements in psychological wellbeing were also recorded with an appreciable decrease after PaddleOn in the percentage of participants reporting having problems with fatigue, feeling less confident about their bodies, feeling less confident in general, feeling down, and having difficulty sleeping (Fig. 2).

The questions relating specifically to how participants felt about aspects of paddle boarding showed that 91% chose 'Very True' or 'True' for the statement "I loved the whole course", 98% for "I learnt a lot of new skills", 96% for "I would recommend this course to a friend", 84% for "I would like to do more paddle boarding", 81% for "I enjoyed the social support of the group", 82% for "Being on the water allowed me to unwind", 70% for "PaddleOn has made more interested in getting fit", 61% for the statement "PaddleOn has improved my confidence", 84% for "PaddleOn has improved my balance", 67% for "PaddleOn has improved my strength" and 53% for "PaddleOn has improved my flexibility"

The PaddleOn pilot programme was reported by the participants to be a very positive experience, with a high completion rate, which appears to be related to the enjoyment of learning new skills and experiencing new challenges, in comparison with some other reported outcomes of exercise programmes that have had poor compliance ⁽³⁾. The amount of

weekly exercise undertaken by participants increased overall and 41% reported weight loss, which is potentially a valuable health change as 52% reported a weight increase since cancer diagnosis and elsewhere this has been linked to an increased risk of cancer recurrence, overriding the benefits of regular physical activity ^(3, 7).

The main change in Quality of Life measures were an improvement in mood, strength and memory, and decreased tiredness, which is in accordance with previous reports on exercise and cancer patients from elsewhere

And here is one of the quotes from participants.

A positive outcome of the PaddleOn programme appears to be not only the reported increased strength, balance and flexibility but also psychological aspects such as increased confidence and overall Quality of Life, and reduced tiredness and fatigue. The positive outlook that many women had at the end of the programme resulted in a high percentage reporting that PaddleOn had made them more interested in getting fit. That an eight week programme can result in such a wide range of positive outcomes provides encouragement for continuing the programme as a means to support improved well-being for women after breast cancer.

The PaddleOn programme is now funded in New Zealand and run through a number of regions by certified pinc or steel cancer rehabilitation physiotherapists together with a certified paddle board instructor. We have opened the program up to men and women with all types of cancer including metastatic cancer if the patient is well enough.

A highlight for me is how much the physiotherapists **love** being involved in **teaching this programme. Getting outside** and seeing people **move and gain in confidence** is a very **rewarding process**.

In summary

- The Next Steps and PaddleOn Programs give physiotherapists working in cancer rehabilitation a chance to:
 - walk the talk, extend their skill range, increase job satisfaction and improve outcomes for their patients
 - and it is beneficial for their own health.
 - I think working together as health professionals and extending the scope of our services will ensure we help more people to reach their potential to live as actively and fully as possible.