

## Resilience: a model for allied health service provision in an oncology setting

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It is now recognised that rehabilitation needs to be treated as a distinct phase in the health care treatment of cancer patients.<sup>1</sup> At Bendigo Health, those who have had treatment for breast cancer have access to a well-established rehabilitation program which is part of a clear treatment pathway. However, other cancer diagnostic groups are not as well serviced and the challenge remains to establish effective and appropriate rehabilitation options for these patients. The resilience program was a pilot project to provide access to a greater scope of allied health services for patients who were undergoing, or who had completed, a course of chemotherapy.

### Cancer in Australia

Cancer is the leading cause of death in Victoria. It affects one in three Victorians up to the age of 75.<sup>2</sup> In 2012, it was estimated that more than 120,700 Australians will be diagnosed with cancer, excluding basal and squamous cell carcinoma of the skin.<sup>3</sup> These figures compare with the 1982 figures of 47,350 and the 2005 figures of 100,514.<sup>6</sup> Whilst improvements in detection have made a significant contribution, a major factor is our population demographics. Cancer occurs more commonly in older people and with the ageing of the population, the number of cancer patients is expected to increase by up to 40 per cent over the next ten years.<sup>2</sup> This has significant implications for rural Australia, when compared with capital cities, the non-capital city areas typically have significantly higher projected proportions of people aged 65 years and over.<sup>4</sup> Alongside this increase in cancer diagnosis, there has been an improvement in cancer survival rates. The five year survival rates have increased from 41 per cent in males between 1982–1986 to 58 per cent between 1998–2004, and from 53 per cent to 64 per cent in females.<sup>5</sup> The net result of this higher incidence and improved survival is the increased prevalence of people with a personal history of cancer. At the end of 2007, there were around 774,700 living Australians, (about 3.6% of the total population), who were diagnosed with cancer in the previous 26 years.<sup>6</sup> This places significant strain on the health system not only to ensure timely diagnosis and effective treatment, but also to ensure that the survivors have access to rehabilitation services to maximise their health outcomes following the completion of treatment.

### Cancer rehabilitation

‘Rehabilitation attempts to maximise patients ability to function, to promote their independence and to help them adapt to their condition. It offers a major route to improving their quality of life, no matter how long or short the timescale. It aims to maximise dignity and reduce the extent to which cancer interferes with an individual’s physical, psychosocial and economic functioning’.<sup>7</sup> In 2005, The Institute of Medicine<sup>8</sup> published a report *From Cancer Patient to Cancer Survivor: Lost in Transition*. In it they described the essential components of survivorship care. “Survivorship care includes four components: (1) prevention and detection of new cancers and recurrent cancer; (2) surveillance for cancer spread, recurrence, or second cancers; (3) intervention for consequences of cancer and its treatment (e.g., medical problems such as lymphedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; and concerns related to employment and insurance); and (4) coordination between specialists and primary care providers to ensure that all of the survivor’s health needs are met (e.g., health promotion, immunisations, screening for both cancer and noncancerous conditions, and the care of concurrent conditions).” It is this third component which is now the focus of greater attention worldwide. Cancer is now being recognised as a chronic health condition with many of the effects of cancer and its treatment causing health concerns for many years following the completion of active treatment. Whilst other health conditions have well established rehabilitation pathways, rehabilitation for cancer survivors has not had the same recognition to make it a standard aspect of treatment. Whilst musculoskeletal, neurological and other chronic conditions all have established outpatient rehabilitation services, the same access to care is not provided to all cancer survivors. At Bendigo Health, breast cancer survivors are the exception. The tissue trauma

clinic has been providing a multidisciplinary rehabilitation service to people who have developed, or who are at risk of developing, cancer. The service is part of a clear care pathway for women who have undergone breast cancer surgery and provides education, assessment, and long term follow up with the provision of physiotherapy, occupational therapy, psychology, exercise physiology and other allied health professionals.

There are a series of unmet needs identified in cancer survivors. Some of these represent the acute toxicities of treatment. Issues such as fatigue and deconditioning, altered cognition, physical dysfunction, pain and psychosocial issues could all benefit from the provision of rehabilitation services.<sup>1</sup>

In its Cancer Action Plan 2008–2011, the Victorian Government identified 4 action areas to address over that time period. Of significance for the provision of allied health services was the identification of supportive care as a key priority area, recognising the need for early detection of supportive care needs through screening, and intervention to support patient and carer. Follow-up care and survivorship issues were identified as an under-developed but important field of cancer service provision.<sup>2</sup>

### **Cancer care at Bendigo Health**

Bendigo Health provides the mainstay of cancer treatment options for the Loddon-Mallee region. Geographically this represents approximately one quarter of the state of Victoria. The resident population of this area is around 250,000 however the catchment for cancer services is much larger with patients travelling from other areas in Northern Victoria and southern New South Wales to access the services which are closest to their homes.

Cancer care at Bendigo Health operates in a multidisciplinary format. Surgical, medical oncology, radiation oncology, pathology and medical imaging specialists present new patients at specific tumour stream meetings. Discussion is then held as to the best clinical options for those patients with those options then being presented to the patient. Other clinical management meetings are also held which incorporate staff from the palliative care nursing and other allied health services.

Although the primary phase of diagnosis and treatment of cancer are well established at the hospital, the additional rehabilitation phase has not yet developed to the same extent.

### **The resilience program**

The resilience program was developed in 2010 as a demonstration project with funding from the Loddon-Mallee Integrated Cancer Service. Initially aimed at patients who had undergone treatment for colorectal cancer, the program was expanded to accept patients with all cancer types excluding breast cancer (given that these patients have access to rehabilitation elsewhere at Bendigo Health.)

The aim of the resilience program was to provide an evidence based, sustainable, patient-centred program that addressed cancer risk factor, side effects of surgical and adjuvant treatment, and supportive care needs within a biopsychosocial framework.

The program was aimed at addressing the gap in service provision. It was recognised that oncology patients present with a range of interacting symptoms including myalgias, arthralgias, fatigue, sleep disturbance, distress and decreased function. There are issues with returning to normal levels of activities including work, and fitness and endurance, and issues of coping with the psychological impact of a cancer diagnosis, its treatment and prognosis.

Secondly it was hoped that the program would provide a rehabilitation option to the medical oncology department. It has been recognised that one barrier to oncology rehabilitation is the sometimes non-existent or often weak interface between oncology and rehabilitation health care providers.<sup>1</sup> This program aimed at providing a responsive service and timely communication to medical oncology staff.

## Preparation for the program

As this was a new program the biggest challenge in its preparation was the access to funding. A successful application to the local Integrated Cancer service provided funding for 2 hours per week each for a project officer and three facilitators (physiotherapist, exercise physiologist and occupational therapist). It also funded the costs for a psychologist to present every six weeks. Dietetics input was gained from the current staffing within oncology. The program was initially funded for a 12 month period however delays due to administration issues resulted in an actual provision period of 7 months.

The preparation for the education sessions required the identification of appropriate outcome measures and determination of topics for inclusion. These were identified from literature reviews, however presenters were flexible in their sessions thereby allowing for inclusion of issues that had been identified at initial individual participant screening and to allow participants to raise specific issues.

## Recruitment

The program was aimed at patients who were at the subacute stage of their cancer treatment (either during or following their chemotherapy) and who were determined by their oncologist to be medically suitable for an exercise program. It was targeted to those who would otherwise not have access to multi-disciplinary rehabilitation, and those with complex needs. Another important consideration was participants' appropriateness for a group based program, and the capacity to attend for the six sessions. Despite education sessions for staff and an awareness program aimed at potential participants, recruitment was a significant challenge for the program.

## Format

A six week rolling group program was decided upon to allow patients to enter at any point and with the flexibility to catch up any absences at a later session. The format included weekly exercise activities which were modified to fit in with the individual needs of the patients. Warm up and stretching exercises were also incorporated to develop appropriate fitness behaviours in participants. Thirty minute information sessions were presented by a variety of allied health professionals including physiotherapist, psychologist, dietitian, and occupational therapist. Topics included return to exercise, pacing and sleep hygiene, coping strategies, return to work and fatigue management, nutrition, community resources and communication and relationships. Each session concluded with therapist led relaxation. Prior to their inclusion in the program, participants underwent a phone screen and a series of individual assessments. Physical assessments included a Timed sit to Stand, Shuttle Walk Test and a Timed up and Go Test. Other screening included the Kessler Psychological Depression Scale (K10), the Distress Thermometer<sup>9</sup> and a cancer specific questionnaire. Participants were reassessed at the completion of the program and at six weeks following completion. Satisfaction surveys were also included at the completion of each session.

## Results

At the commencement of the program all participants indicated their knowledge of coping strategies, exercise and relaxation was low, as was confidence to return to regular activities and to seek community assistance. In contrast, the confidence to manage treatment related symptoms was rated as "good". This is likely to be due to the extent of symptom management education provided by oncology staff. It was noted that the participants of the program were typically of working age, many with the additional responsibility of children at home, and were previously high functioning. Consistent through the group was the presence of de-conditioning, and in some cases peripheral neuropathy was impacting significantly upon mobility. Participants showed slightly raised measures on the K10 and distress thermometer.

Post program results indicated that patients were able to maintain or to improve their function over the course of the program regardless of whether they were still receiving chemotherapy, and distress and depression scales were within normal limits.

To inform the final report for the funding body, semi-structured interviews were conducted by a staff member not involved in the running of the program. During these interviews participants revealed that:

- the resilience program led to improvements in confidence
- the program content and resources were essential
- the feeling of being lost and isolated was the greatest need addressed by the program
- the resilience program made them feel connected and supported, impacting positively upon wellbeing and sense of self.

It was surmised that the feeling of support could be attributed to the group format and the informal discussions about treatment effects which were facilitated within this setting. This had the effect of “normalising” issues and led to the sharing of individual coping strategies thereby highlighting competencies rather than skill deficits.

Based upon the program analysis it was recommended that the program continue. It was felt that the measures used provided facilitators with information which could be utilised to refine the program at an individual and group level, and also allowed for identification of individuals who may require individual follow-up. Feedback communication was built into the program such that the oncology department and the patient’s GP were kept informed of participation and outcomes. It was identified that due to the level of supervision required for some patients, a group size between four and eight would appear optimal. The inclusion of additional validated measures would provide the opportunity for the gathering of strong qualitative data to determine any additional needs of this patient group.

Limitations to the program were also identified, the first of these being the difficulty in recruitment over the time period. Sustainability was also an issue. As the majority of staff time was spent in direct patient contact, little time remained for refinement of the program and as staff had limited time allocation for the group program, access to individual follow-up was constrained. The majority of patients involved in the program were from Bendigo or were in a position to travel to the group. The need to address the provision of the service to patients from more rural areas has been identified and requires further investigation into potential local solutions. Finally the most significant issue for the program was a lack in ongoing funding without which the program could not be continued.

## Conclusion

The resilience program was aimed at the providing cancer patients with rehabilitation options in an outpatient setting. Whilst the participants clearly identified benefits from their involvement in the program, the lack of ongoing funding has frustrated attempts by allied health clinicians to provide an ongoing service to this patient population. Further avenues to secure ongoing funding need to be investigated to allow the development of a service to a client group that is set to increase markedly in the future. Health Care providers need to be aware of the impact of the cancer disease trajectory and its treatment, upon individuals, and to make a commitment to the provision of rehabilitation options in appropriate settings.

## References

1. Silver K, Gilchrist L, Cancer Rehabilitation with a focus on evidence-based outpatient physical and occupational therapy interventions. American Journal of Physical Medicine and Rehabilitation 2011; 90(supplement): S5 –S15
2. Victorian Government Department of Human Services. Victoria’s Cancer Action Plan 2008–2011. Ability Press 2008
3. Australian Institute of Health and Welfare Cancer in Australia: an overview 2012 [cited 20 Feb 2013]. Available from URL: <http://www.aihw.gov.au/publication-detail/?id=60129542359&tab=2>

4. Australian Bureau of Statistics Future population growth and ageing. Australian social trends 2009 [cited 10 March 2013] Available from URL: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features10March%202009>
5. Australian Institute of Health and Welfare. Cancer in Australia: an overview, 2008.[cited 8 March 2013] Available from URL <http://www.aihw.gov.au/publication-detail/?id=6442468196&tab=2>
6. Cancer survival and prevalence in Australia: Period estimates from 1982 to 2010 [cited 9 March 2013] Available from URL: <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737422721>
7. National Institute for Clinical excellence (NICE). Improving Supportive and Palliative Care for Adults with Cancer London: National Institute for Clinical excellence 2004
8. Hewitt M, Ganz P (eds) From Cancer Patient to Cancer Survivor: Lost in Transition. National Cancer Policy Board Washington: National Academies Press 2005
9. National Comprehensive Cancer Network, (NCCN) Clinical Practice Guidelines in Oncology: Distress Management. National Comprehensive Cancer Network 2010