



10th National Psycho Social Oncology Conference

Shaking Up Psycho Oncology Practice, Practicalities and Possibilities
18th and 19th November 2011, Novotel Tainui, Hamilton

International Speakers

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Screening for cancer distress: delivering holistic triage and care

Dr James Brennan

Thanks to the emergence of hospices and palliative care the physical suffering associated with cancer has never been better controlled, at least in countries which have these services. It is the psychosocial suffering associated with cancer that bears a much closer resemblance to historical images of cancer as a wasting and painful disease.

Over past decades a number of attempts have been made to respond to the enormity of cancer distress. The field has gradually moved away from the idea that distress can be sensibly equated with psychopathology, and these days it is generally agreed that distress is a multi-factorial concept involving physical, psychological, social, and spiritual causes. But if hard-pressed oncology services are to respond to distress, the Sixth Vital Sign as IPOS have proposed, then they must first be asking the right questions of their patients and, in view of patients' reluctance to volunteer their concerns, be prepared to be proactive in doing so. It is also essential that screening for distress is acceptable to patients and that the language used is easily understood by them. Thus we need an efficient, effective yet humane way of identifying and responding to cancer distress, one that is warmly welcomed by patients and staff alike. This paper will describe some preliminary work in this direction.

The Distress Thermometer, first reported by Roth in 1998, has since been adopted by the NCCN. This simple idea of using a visual analogue scale to represent distress, is now the starting point for a method of holistic assessment and triage developed in Bristol. The method of screening described in this paper offers front-line healthcare staff a structured, yet collaborative way of discovering their patients' main sources of distress. With training and good informational resources, they can respond usefully to these difficulties, as well as normalise the patients' understandable emotional concerns (i.e. fear, sadness, anger). When routinely used as a part of the patient's care pathway, a holistic treatment review makes it less likely that psychological difficulties become pathologised by professionals or seen as a source of shame for patients. This paper describes this adaptation of the DT and some of the research and other initiatives associated with it. In particular, it will report on a study designed to refine the questions we ask when screening for distress, a methodology that may be useful in a New Zealand context.

Adjustment to cancer

Dr James Brennan

Psychological theory helps therapists formulate an understanding of their clients' underlying emotions and mental processes. Theory is particularly important in the field of cancer where the patient may be managing many sources of distress, some of which are driven by medical necessity or disease progression. Whatever its prognosis, a cancer diagnosis heralds far-reaching changes for the person and their loved ones, often a daunting and exhausting trek into an unknown future. Change and uncertainty are the hallmarks of the cancer experience. The rapidity with which normal life becomes transformed into routines dictated by treatment (rather than choice) affects the patient and everyone close to them.

This paper sets out a model of psychological adjustment to major life transitions, as people reconsider some of the basic assumptions by which they have thus far lived their lives. Against this backdrop of personal turmoil healthcare professionals offer some of the most notoriously difficult and energy-draining treatments in all of medicine. While this confrontation with mortality can lead to high levels of distress, they can also sometimes yield helpful conclusions which stimulate personal growth. The Social Cognitive Transition model of adjustment accounts for this paradox, as well as the emotions that are evoked as people negotiate the changes and transitions that cancer and its treatment involve. Finally, the model has implications for the role of psychological therapists.

Cancer survivorship: myth or reality?

Dr Pamela McGrath

Recent advances in the care and treatment of cancer mean that more patients are now achieving a cure, or at least substantial lengths of time in remission. The perspective for supportive care in this area has now changed from responding to the psychosocial needs associated with acute illness to supporting individuals to live with a chronic condition. Indeed, the notion of 'survivor' has now been mainstreamed and accepted in oncology, supportive care and in the media. The assumption is that this is a positive term embraced by individuals diagnosed with cancer. This presentation challenges many of the assumptions associated with the term 'survivor', discussing findings from a recent study on survivorship in relation to haematological malignancies conducted in collaboration between the International Program of Psychosocial Health Research and the Leukaemia Foundation of Queensland. The findings indicate caution is needed in the use of the term as the majority of haematology patients interviewed did not identify with the term because it creates too much focus on the disease and interferes with the major coping strategy of 'getting on with life'.

Travel-based relocation: The New Zealand experience

Dr Pamela McGrath

This presentation extends prior research on relocation for specialist treatment to include a focus on factors specific to the New Zealand context based on recent research conducted by the International Program of Psycho-Social Research in collaboration with the Leukaemia and Blood Foundation. The findings highlight the need to reconceptualise relocation as defined by two concepts: 'travel-based' relocation and 'accommodation-based' relocation. In New Zealand, as elsewhere, cancer supportive care organisations are increasingly providing volunteers to assist with travel. Such practical volunteer assistance is important, as is financial support through government subsidies to cover the cost of such travel. The insights from the study affirm the importance of health professionals who are supportive and creative in their efforts to assist people to return home. The presentation concludes with a discussion of the Leukaemia and Blood Foundation's initiatives to translate the findings into practice.

Shaking up the Living Well Programme – development of Kia Ora e Te iwi

Pauline Wharerau and Hazel Neser

The Living with Cancer Education Programme was brought to New Zealand in 1990 from the Victoria Cancer Council, Australia. Since then, the programme has been delivered to support patients/family/whānau/carers affected by cancer wherever they are in their journey. During 2009, the name of the programme was changed to the Living Well Programme (LWP) to reflect recent developments in cancer survivorship.

A key aim of the programme is to provide education about cancer, its treatments and self-management of the after-effects of cancer to ensure that patients' and their family/whānau journey is as smooth as it can possibly be. Demystifying cancer and reducing personal distress in this way can be very empowering for patients and their family/ whānau.

More recently, the Cancer Society has looked at developing ways to increase Māori participation in this programme in order to reduce barriers in access to this service. During 2010, a pre-pilot was run at Kokiri Marae, Seaview, and Wellington, followed by regional pilot programmes throughout the country in 2011. All facilitators were Māori Health Providers. Evaluations of content and delivery from these pilots provided evidence that the LWP needs to be delivered with a kaupapa Māori focus. *Kia Ora e Te Iwi* grew out of this. *Nau te rourou, naku te rourou ka ora te manuhiri*

On the cancer journey? Don't forget the children

Penny Parsons, Jenni Willson, Sheryn Buckley, Lynda Lakin

When a loved one has a cancer diagnosis, they embark on a journey from diagnosis, through treatment and beyond. Whether the beyond is cure, remission or sadly death, the family is an integral part of the journey. Families involve children if the journey is being made by a parent or grandparent, or a sibling if it is a child with cancer.

Rainbow Place supports children and young people when a loved one has a serious illness. Unlike Hospice (our umbrella organisation) Rainbow Place supports families throughout the cancer journey whatever the outcome.

During the past eight years, Rainbow Place has learned through experience and research, how best to support children and young people through change, loss and grief. A recent in-depth review by an eminent international researcher, Professor Philip Darbyshire, has given the team 'pause for thought' about ways of working with their vulnerable client group. The caseload keeps growing, times are hard economically ... how can we continue providing an excellent service and keep within budget?

The Rainbow Place team will share snap-shots from their practice, working with young clients, and explore ways to move forward following recommendations from Professor Darbyshire. They believe passionately that their young clients deserve the very best support throughout the cancer journey of a loved one. The team is ready willing and able to embark on the next stage of their journey, the destination ... Rainbow Place, a service firmly grounded on sound research and best practice.

CANcer Spring: All about me

Debbie Mills Henry

The presentation will demonstrate how the use of group work with children and teens affected by cancer can be extremely beneficial, utilising personal quotes from children and families, photos, and children's art work I will explain how groups designed by her utilising her skills as a qualified play specialist provide children supported by the L&B foundation (Auckland region) with additional support.

I use specialised creative play therapies such as throwing clay, creating volcanoes, weaving, mask making, to allow the group to safely express feelings relating to their illness or that of their sibling, mum, dad or other whanau member.

Health questions are answered through the use of hospital play preparation dolls and the support of a qualified nurse.

The group offers the 'time' to learn new skills that may be required at home such as cooking through team work they can learn how to cook simple things such as bolognaise, eggs, toast and how to make a cuppa, afterwards they get to eat their culinary creation! You'll be amazed what comes out of a conversation when cutting onions.

Groups give permission and a safe outlet for having 'fun' and just being kids.

What are the benefits of outings or daring adventures for a group of children/teens affected by cancer?

CANcer Spring Groups offer support by opening the doors to children's minds, assuring them that are NOT alone in this mission, there are others that are going through this. Children and teens CAN Spring forward through cancer as long as they and their whanau have the appropriate support.

Te Awa: the river

Ellyn Proffit

Being an adolescent or young adult in today's times can be hard, like coming to grips with bodily changes, adjustments in relationship roles, deciding on studies and careers in life and keeping up with the fast advances in technology!

Chuck in a life threatening illness such as cancer and one can find themselves on a very turbulent flowing river otherwise known as the 'cancer journey'.

This session will discuss that journey – using 'the river' analogy as a tool to assist young people and their families to talk about different aspects of their cancer diagnosis. These aspects can range from - coping with the impact cancer has on relationships and friendships, treatment pathways, emotional & psychological coping along the cancer trajectory.

Come and experience 'Te Awa'.

Metacognitive therapy for anxiety in cancer patients and their families

Kathryn Taylor

In this presentation I will discuss how Metacognitive Therapy may be used to benefit cancer patients and their family members who are experiencing anxiety. As there has been a recent increase in research into identifying patients experiencing significant levels of psychological distress, it is vital that work is also put into developing a range of effective psychological therapies to offer them. Cognitive Behavioural Therapy (CBT) has been the most widely used individual therapy to treat psychological distress, including anxiety and depression. Clinical trials evaluating the efficacy of CBT in cancer patients suggest some benefit, however, as with all psychotherapies a significant minority of patients do not benefit. Therefore it is important to develop new therapies that may suit these patients. Metacognitive Therapy (MCT) is a relatively new therapy to come out of the cognitive therapy stable. Developed by Adrian Wells, MCT takes a new approach by working with the patient's metacognitions (cognitions about cognitions) rather than the content of the cognitions themselves as in CBT. This approach may have some advantages when working with cancer patients who may find dealing with the content of their thoughts to be distressing. In this presentation MCT is described and its suitability for an oncology setting is discussed. Case studies are presented for both patients and family members who are experiencing significant levels of distress.

Creative expressive therapy: the 'soul's medicine'

Charmain Smit

Every human being has the capacity to be creative. This presentation will provide conference attendees with a glimpse of what we do at the creative centre at Hospice Waikato and will show how the creative arts can be used to assist clients to explore difficult emotions such as fear and anxiety.

Making art/objects can help one to communicate with others when words can't be found or are inadequate to describe what is really happening. Art can be executed in any medium at the creative centre at Hospice we use mainly painting, creative writing, decoupage, mosaic, collage and altered books.

In this presentation case studies are used to demonstrate outcomes as well as reflections from my own journey through grief. When using the arts for self-healing or therapeutic purposes we are not concerned about the end product it is more about the journey.

We use the arts to let go, to express and to release. We gain insight by studying the symbolic and metaphoric messages. By going deeper than words we give voice to our soul. Transformation begins when we are able to see ourselves, our lives, and our experiences differently.

When words fail art(s) speak.

Compassionate listening: evolving practice

Peter Kimble

An autoethnographical journey to discover the art and heart of my nursing practice. In this journey of reflection I will discuss how to reveal the patient's story through compassionate listening and how integral this is for healing to occur. Special moments of human connectedness are often shared. Through this process nursing practice evolves and becomes more meaningful for both nurse and patient.

“The speculum bit is the easy bit, eh!” - Psychosocial challenges for women having treatment for cancer of the cervix

Clare Mills

Cervical cancer, deemed a preventable cancer, causes the deaths of 80 women in New Zealand annually. Age at first diagnosis is younger for this group than other adult cancers, occurring in women aged 20 – 50 years. The average age of women treated for cervical cancer in 2010 at Waikato DHB was 49 years.

As Brachytherapy nurse at Waikato DHB I work closely with these women as they complete concurrent external beam radiation, chemotherapy and brachytherapy. This demanding regime presents psychological and emotional challenges alongside physical ones. Many of these women have young families and partners often reliant on them financially and they are also involved in their wider communities.

While undertaking research with this cohort, checking smoking history and previous history of abnormal smears, I became interested in assessing how these women viewed the brachytherapy procedure itself. I conducted an audit, post-treatment, of the 2010 women (n = 15), to assess the present service and how it could be improved.

Feedback from these women revealed some gaps in the information they had been given and also highlighted concerns about follow up once treatment had been completed. I found this very helpful and these issues are being addressed.

The therapeutic potential of cancer nursing in the outpatient setting

Jenny Cameron

How do oncology nurses support cancer patients in what has been described as ‘the dehumanizing factory-like culture of the day stay chemotherapy unit?’

The culture and context of the day stay chemotherapy unit can have a positive or negative effect on the patient's ability to cope with their cancer treatment. Environmental factors such as a lack of space or privacy, together with the biomedical perspective of treatment regimes may inhibit nurses in the care they would like to deliver.

These factors can add to the perception that nurses are reduced to mere technicians running between alarming infusion pumps, having little opportunity to address caring interventions which remain the essence of nursing.

The purpose of this presentation is to identify what the literature reveals about the specific needs of cancer patients in the outpatient services, and the nursing care that makes a therapeutic difference to their cancer journey. Also addressed in the literature are the phenomena's of positivity, resilience and self care, the positives and the negatives.

In summary, research tells us that oncology nurses working in the outpatient area are well positioned to develop ongoing, understanding, supportive and therapeutic relationships with cancer patients. However this may depend on the communication skills of an individual nurse, and their ability to identify and address information and psychosocial needs.

“Nursing in Exile”: Nurses grief – a reflective case study

Madeline Fiddes

Mrs. B was admitted with uncontrolled pain. She had already had all she could have had in a very short period of time but the pain remained relentless – its claws dug into her and took her breath away leaving her whimpering in pain. Mrs. B did not scream, yell or curse – it almost looked like she was in a trance – her lips moving continuously... Her husband was beside himself – he took Mrs. B's head and shook it, trying to rid her of the pain or shook her out of the trance. Tears were streaming down his cheeks, his shoulders shook and he sobbed! Help her! He begged. Can't you sedate her? The Registrar knelt beside her and asked whether she was praying – Mrs B said yes and whispered – “Please kill me” The Registrar started to pray and read verses from the Bible – the minutes were ticking and other patients were waiting but time stood still in room 29...

Grief is often experienced by healthcare professionals following the death of a patient. At times grief plays a much bigger role than expected, leaving the health professional in exile. Nurse's grief is often ignored or suppressed. Suppression of grief can lead to burnout, compassion fatigue and moral distress.

This presentation reflects on a case study and a literature review. What are the factors that increase the risk of grief for health professionals? How can health professionals identify risks of compassion fatigue? We are continuously exposed to loss and grief in palliative care – how can we managed grief and loss in a constructive way?

My Health Matters: a guide to managing your treatment and care record

Sarah Penno

My Health Matters is a tool to encourage and empower patients to more actively engage in their health care. In anticipation of the soon to be launched six month pilot in ADHB, this presentation will outline the evidence supporting the development of “My Health Matters” and the proposed integration into care.

Evidence from overseas has shown that increasing patient involvement in shared decision making and facilitating greater active involvement in patients self-managing their own health care improves patient outcomes. It is also a legal requirement in New Zealand that all health care providers ensure patients have access to information to the level they require and in a format they can understand. It will act as a repository for:

- all specific cancer information

- local treatment information
- laboratory/scan and test results
- notes from clinicians/health care team (including treatment decisions/care plan)
- specific questions/answers (including the potential cost of their care)
- self reflection
- monitoring of side effects/symptoms
- record of medications used- both prescribed and over the counter or alternative medications
- other health issues/concerns
- any other information that the individual patient requires

A secondary but potentially equally important function of My Health Matters is to enhance communication between health care team members. Access to consistent information strengthens communication and enhances patient outcomes.

My Health Matters could also help to decrease inequalities by prompting more complete access to care, increasing communication opportunities particularly regarding management of co-morbidities, and potentially reduce wait times for Maori patients.

Pushing the possibilities: consumers and health professionals co-design web videos on breast cancer

Dr Chris Walsh with Rowena Mortimer, Gillian Wintrup and Jenny Williams

Purpose: This paper describes the collaborative approach between consumers and health professionals to produce web-based videos designed to support those affected by breast cancer. This project demonstrates the success of using the combined talents and experience of consumers and health professionals to co-design appropriate supportive information and resources.

Data sources: Narratives from fourteen women, one man, four family members and five health professionals form the basis of these videos. Initial drafts of the videos were reviewed by health professionals for accuracy. This review was critical to the quality of the web videos because balance was needed between the evidence based practice of health professionals and the experiences of those with breast cancer.

Findings: The professionally produced and edited web videos feature a range of identified themes. Specifically, the psychosocial impact of breast cancer is explored in the themes; family supports, relationship with partners, help getting through and life after breast cancer. Whilst consumers acknowledge the key role health professionals have in guiding them through their breast cancer journey they also value highly the support from family, friends and others who have been down the same path.

Conclusion: The practice of health professionals is interwoven with experiences of breast cancer patients. The possibilities aspired to have achieved a “first” in cancer supportive care in New Zealand. To date, feedback from the web videos supports the ideology of a consumer/professional interface in the provision of supportive cancer care.

Cognitive changes with adjuvant therapy for breast cancer

Dr Michael Jameson

BACKGROUND: Patients undergoing adjuvant therapies following surgery for breast cancer, such as chemotherapy and anti-oestrogen hormone therapy, commonly complain of impaired memory and concentration. While cohort studies had suggested an objective deficit in such patient groups compared

to controls not treated with these therapies, adequate longitudinal studies had not been reported, nor had the role of other possible contributing factors such as mood disturbance and menopausal status.

METHODS: This study aimed to examine:

1. the incidence, time course and recoverability of deficits in cognitive function (verbal memory, concentration, speed of mental processing and motor functioning)
2. changes in quality of life, fatigue and mood
3. the roles played by menopausal status, fatigue and mood in cognitive functioning.

Subjects included women who had undergone definitive surgery for invasive or in situ carcinoma of the breast and required adjuvant therapy (any of chemotherapy, hormone therapy or radiotherapy). A longitudinal repeated measures design was used, with each case acting as their own control. A battery of tests was undertaken at baseline (after their first oncology appointment) and repeated at 3, 6, 12 and 24 months.

RESULTS: 200 women have been recruited as planned into this study. The final subjects have now completed their 12 month assessments and analysis of the results is underway, and will be presented.

CONCLUSIONS: This longitudinal design is likely to be much more informative about the degree of change in specific aspects of cognitive function in individuals and groups compared to cohort studies. The results may offer insights into the nature, incidence, time course and recoverability of any such changes, and enable clinicians to better inform patients of likely risks and outcomes.

Liquefaction holding back supportive care infrastructure: psychosocialspiritual assessment and referral processes.

Richard Eagan

Background: Attending to the psychosocialspiritual (PSS) needs of those affected by cancer is widely mandated. This project examined supportive care assessment and referral practices among New Zealand (NZ) oncology-focused healthcare professionals.

Methods: A mixed methods approach involved key informant interviews (2009), with healthcare professionals (n=24) throughout NZ. Additionally, an online survey was conducted (2010) of oncologists and oncology focused nurses.

Results: The 24 interview participants included 5 oncologists, 7 oncology nurses, 4 GPs, 3 Māori navigators, 2 psychologists and a social worker, psychiatrist and surgeon. The questionnaire resulted in 199 completed surveys (response rate 28%). Both studies affirmed that PSS needs are important and at times unmet. There was a very high awareness of some support services, but the full scope of the service may not be well understood. Most at risk were identified as those who were isolated and family members of cancer patients. Nurses were the key professionals in the assessment and referral process. Assessment for PSS need is largely informal, intuitive and based on experience, with assessment tools seldom used. Referral processes varied, with many support services offering formal systems, though they were not always used. Māori affected by cancer were considered to face significant gaps and barriers.

Conclusions: There are further opportunities to improve PSS care related to gaps and barriers, particularly focusing on upstream issues such as Ministry of Health priorities, infrastructure for

PSS care processes and meeting mandated culturally competent, holistic and patient-centred approaches.

Taking survivorship care planning forward in New Zealand

Jo Ansen

This presentation will look at the increasing focus on cancer survivorship planning and programmes in NZ and will discuss opportunities for taking a coordinated approach to future development.

The focus on cancer survivorship has been growing in NZ over the past few years. National forums have been held in Wellington in 2010 (facilitated by Manawatu Cancer Society / CCN / Wellington Cancer Society) and in August this year (facilitated by Wellington Cancer Society). These forums have highlighted both activity around survivorship care planning and the development of support programmes. Presenters and participants at these forums have expressed their desire to see a coordinated approach to future development. The Guidance for Improving Supportive Care for Adults with Cancer in New Zealand and its subsequent implementation plan provides a vehicle for taking this work forward.

An interest group in the Wellington region has been established to progress survivorship planning and this group is in the process of identifying an approach which will have local applicability but also may help shape regional or national activity. These opportunities will be discussed.

From survive to thrive: living full after treatment

Dr Kieren Faull

The presentation outlines an innovative holistic approach, the content and outcomes of an intervention that assists those with cancer to maximize health and wellbeing because of their cancer experiences rather than in spite of this.

The quantitative and qualitative findings from a pilot study are included while the results of 12 years of research of post-traumatic growth formed the framework for the approach and content.

The results both the pilot study and the research providing the framework and content indicate that there are significant benefits and potential from this intervention.

Poster submissions

Nurse-Led Telephone Assessment Clinic: Adjuvant Endocrine Therapy

Rachel Collier and Lyn Little, Waikato District Health Board, Breast Cancer Clinical Nurse Specialists

Five years on: the progress of Sweet Louise Support Services.

Sinda Hall – Senior Support Co-ordinator, Sweet Louise.

A partnership health promotion strategy to promote bowel health for Māori males

Judy Warren, WaikatO District Health Board, Colorectal Cancer Clinical Nurse Specialist

Assessing Distress in Cancer: Use of the Waikato DHB Cancer-Related Distress Tool

Stephanie Campbell-Wilson, Waikato District Health Board Gynaecology Cancer Clinical Nurse Specialist