

# **Psychosocial Oncology New Zealand Conference 2008**

## ***Winds of Change: Ideas, Innovation, Initiatives*** **Palmerston North 16-18 November 2008**

### **Models of psycho-oncology and integrated care: Developing a seamless pathway for those on the cancer journey. True colours in the winds of change**

Cynthia Ward & Stephen Parkinson

True Colours Charitable Trust

True Colours Charitable Trust provides an integrated model of care that is family focused and strengths based. Its purpose is to assist children and young people who live with serious and life-threatening illnesses. True Colours provides specialist nursing support and psychosocial care, and aims to enhance the quality of life for the whole family. This integrated model of care is an approach that fits well in caring for children and young people with oncology illnesses and recognizes the diversity of needs pertaining to this population group. Achieving quality deliverance of services to meet these needs requires a collaborative working style; inclusive of other health providers. True Colours provides a continuum of care from the time of diagnosis, whether that is with hope for a cure, or through to bereavement if cure is not attained. A range of skills and expertise is required to care for children and young people living with cancer. The provision of care needs to be inclusive of physical symptom control and psychosocial care to minimize the feelings of grief, loneliness and anxiety. A case study will be presented to demonstrate the pathway of care provided to a family highlighting the collaborative, integrated approach between primary, secondary and tertiary providers; and the impact of this support on the family. A seamless and coordinated service relies on both specialist and generalist skills to provide equity in the delivery of care across urban and rural regions. How this care is managed is pivotal to the family's experiences of how well supported they feel on their journey with cancer.

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### **CanTeen: How we support, develop and empower**

#### **Using research to inform our work with young people living with cancer**

Michelle Thomas & Eve Coster

CanTeen NZ

CanTeen is dedicated to helping all young people living with cancer, as either patients or family members. Australia CanTeen worked intensely since its inception in 1985 to ensure quality support for 12-24 years olds facing the challenge of cancer in their lives. In recent years CanTeen has acknowledged and focused on the need for research to inform and support our programs and service delivery. This has resulted in an extensive research agenda over the past two years into the needs of our membership and the best ways to meet them.

This presentation will recount the strategies and methodologies put in place in for CanTeen to discover the profile and needs of young people living with cancer, including demographics such as age gender, socio-economic status and ethnicity. It will consider the role of the organisation – where does CanTeen fit in the journey for an adolescent with cancer and how satisfied is the membership with the services being delivered. We will present the services CanTeen has to offer its members and the benefits of our programs and service delivery to members. We will also outline the referral process to the organization and how young people are invested in all areas of the organization.

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## **Emotional and interpersonal aspects of fertility damage from cancer treatment in pre-menopausal women**

Sarah Hunter

The aim of this interpretive descriptive study is to ascertain and articulate the emotional and interpersonal aspects of fertility damage from cancer treatment in pre-menopausal women, as a factor in their ongoing quality of life. As diagnoses of cancer are made earlier in the course of the disease and treatments become increasingly effective, survival rates from cancer are rising. This leads to an elevation of the importance of issues related to ongoing quality of life, including fertility.

There are differing estimates of potential fertility damage for pre-menopausal women undergoing cancer treatments, ranging from 30-95%. These differences reflect the influence of the diagnosis, the type and duration of treatment, and the age of the woman during treatment. A further complicating factor is the difficulty inherent in diagnosing permanent ovarian failure, which, other than gynaecologic surgery, is the primary etiology of fertility damage from cancer treatment. Whereas the means to successfully preserve fertility in men prior to cancer treatment is simple, physically harmless and well established, such measures for women are currently much more complicated, and much less successful. This means that in addition to the emotional trauma that usually accompanies a cancer diagnosis, and the need to undergo harsh treatments, women aged 20-50 also face the very real prospect of irreversible fertility damage. The critical need for research pertaining to the psycho-social aspects of fertility damage from cancer treatment and its impact on quality of life is well recognized. In response, this study will contribute to both local and international knowledge of the impact of fertility damage from cancer treatment. Chronic Sorrow Theory underpins the study and will be used to inform analysis of the data. This paper will report on the early findings from face-to-face interviews with New Zealand women who are 1-5 years from their initial diagnosis and treatment.

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## **Psycho-oncology meta-analysis: Moderators of treatment effectiveness**

Heather Heron, Don Baken, & Shane Harvey

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Previous meta-analyses of psycho-oncological treatments for distress have produced effect sizes for different treatment types (education, social support, CBT, etc.) but have not attempted to 'crunch' the mass of variables relating to primary trial design, therapy content and delivery, and patient characteristics to elicit more than a very few moderators of efficacy. It is hoped that by conducting the most comprehensive literature search to date, and by building upon the categorisations of others, this study will make some sense of the array of variables to bring focus to both productive and unproductive approaches to research and practice. We take an empirical approach to weighing primary trial design quality, meaning that data from both randomised and natural experiments has been collected for analysis. The impact of various trial design features (external and internal validity) upon effect size will be ascertained before the data set is cut for substantive analysis. By this means we should avoid excluding data on the basis of mere assumption as to its strength, ensuring the broadest data base scientifically justifiable. Gross effect sizes will be computed for depression, anxiety, and psychological distress outcomes, and then according to our range of moderators, namely: patient variables

including sociodemographics, premorbid psychological and cancer status, and social support; and therapist and therapeutic technique variables, including specific treatment components, general treatment types, theorised mechanisms (efficacy, coping, self-esteem), and nonspecific/delivery mechanisms. The longevity of treatment impacts will also be analysed. At time of writing, data collection is being completed. It is hoped that by conference date analysis will be sufficiently advanced to allow presentation of some findings, including discussion of interesting outliers.

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### **A qualitative study exploring factors impacting effectiveness of POS interventions for clients with colorectal or breast cancer and their families/ whanau**

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In January 2006 a specialist Psycho-Oncology Service (POS) was established by the MidCentral District Health Board in partnership with Massey University. This paper will present the initial findings from a qualitative study exploring clients' lived experiences of using the POS at Massey University.

Approximately 16,000 people develop cancer each year in New Zealand and by 2011 this level is predicted to increase to 22,000 (Gavin & Marshall, 2001 as cited in Cancer Society of New Zealand, 2004). The psychological impact of a diagnosis of cancer may include anxiety, pain, depression, delirium and fatigue (Holland, 2003). The impact of a cancer diagnosis is not isolated to the patient; research has shown that 18-30% of a cancer patient's adult relatives suffer from depression (Edwards & Clark, 2004).

The initial findings presented arise from the thematic analysis of interviews with former POS clients. Client interviews were confined to those with colorectal or breast cancer and family/whanau members. This study will add to the limited pool of New Zealand and International research in evaluating what factors may have an effect on the psychological interventions provided for cancer patients and their families. The results of the study will help to refine and improve interventions offered and forms part of a planned evaluation of the POS.

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### **The use of mindfulness meditation for people living with cancer**

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Mindfulness meditation is a process of focussing on the here and now - a way of learning to relate directly to challenging and difficult aspects of life and illness. It offers a way to become more aware of the present moment, and cultivates greater balance, calmness and peace of mind. Many studies have shown significant benefits from the use of mindfulness meditation for people with cancer including improved psychological functioning, reduction of stress

symptoms, enhanced coping skills and improvements in overall well-being.

A mindfulness approach has recently been incorporated into the Cancer Society of NZ, Auckland Division's Relaxation and Meditation programme. The central focus of this approach is teaching the use of mindfulness-based meditation techniques to help people with cancer cope with the impact of stress and the challenges that illness and treatment can bring to their lives. The use and benefits of specific mindfulness techniques will be discussed and a practical example of a mindfulness exercise will be conducted.

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### **Perceptions of death and the specific effects of death related issues on the identity development of radiation therapy students**

Gay Dungey

The aim of this research was to determine what effect treating cancer patients has on the student's ability to develop their own identity. Because radiation therapy students treat cancer patients a part of this study explored what perceptions of death young people develop and what influence on their identity formation does this specifically play. The literature indicated that radiation therapy students are likely to have clear perceptions of the finality of death, and have probably experienced a death-related event. Female students are likely to be more compassionate about death related issues and be more able to express compassion than their male counterparts. All students are more likely to worry about death occasionally, and are more likely to talk to each other about death rather than their parents. Due to their age, they may believe in some kind of non-corporeal continuation. If they do not believe in non-corporeal continuation, they may engage in risk-taking behaviours, especially if they have lost someone close to them, and even more so if they are male. Because radiation therapy students treat cancer patients, they could report that their life is meaningful, as a means of coping with the potential trauma and emotional aspects of the job. A qualitative case study approach was chosen to complete the research and all of the 30 enrolled stage two students in 2004 were given the opportunity to complete an open-ended questionnaire, of the 30 students 21 responded.

It is concluded that this cohort of radiation therapy students is developing a new set of values, beliefs and goals as a direct result of their interaction with the cancer patient. They had all experienced a death related event, and understand the finality of death but not necessarily reflecting on their own death. It was found that they do talk to their parents about death related events particularly cancer. Males in the class were as compassionate and expressed as much compassion as their female classmates. Several students reported that their life was meaningful due to their interaction with the cancer patient but they found it difficult to deal with the death defying society they live in. With reference to Marcia's (1966) status levels of identity some students are actually expressing a firm sense of self and an achieved identity status with death related issues having a positive effect on their lives. For others the realisation of what they are doing for a career and trying to justify it to the world around them has left them struggling to answer the "who am I" question making it difficult for them to retrieve themselves from a state of moratorium, or even one of the lower identity statuses, into an achieved status.

**NB:** The overview of this research was presented at PONZ 2006.  
This paper is exploring a specific part of the research in more detail.

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## **Supporting the supporters: A randomised trial of interventions to assist cancer support group leaders and their members**

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**Background:** In 2006 a national survey of Australian cancer support group leaders was conducted to investigate unmet needs and preferences for support or training. Survey results found considerable variation amongst leaders in group facilitation skills and training, geographical location and gender. Despite this diversity, participant preferences for interventions to assist them in their leadership role were surprisingly uniform. In line with these preferences, three interventions were developed each with a different method of delivery. The current study aims to evaluate the effectiveness of the interventions and assess their cost in terms of resources and time, and evaluate their impact on the members of cancer support groups.

**Method:** To develop and evaluate by randomised trial, three interventions; specifically, a website and discussion forum, DVD and manual, and 2 day face-to-face training workshop. Leaders were stratified and randomised to receive the minimal intervention (access to the website and discussion forum) or the intensive intervention (access to the website and discussion forum, DVD and manual and training in group facilitation). Leaders and their support group members were assessed using standardised quantitative measures and qualitative interviews to determine the direct and indirect impact of the interventions.

**Results:** Sixty-five leaders (intensive n= 35; minimal n=30) participated in the trial. Baseline and post-intervention data comparing the two study groups' psychological wellbeing and leadership self-efficacy and confidence will be presented. Data measuring the health-related quality of life, social support, ability to cope with cancer and group satisfaction of support group members will also be reported.

**Conclusions:** This is the first study to comprehensively evaluate by randomised trial, the effectiveness of various training strategies to improve the skills of cancer support group leaders. It is anticipated that the interventions will enhance the support group experience of both leaders and members.

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## **After cancer treatment: Can a multi-disciplinary program improve post-treatment outcomes for survivors?**

Tara Stern

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Following cancer treatment, many people feel disconnected from their cancer care centre and have many unanswered questions regarding the impact of having cancer and their future. Psychosocial care of cancer patients needs to extend beyond the treatment phase, as psychological, physical, social and practical concerns do not simply resolve upon treatment completion. In Australia, post-treatment psychosocial programs and research have been minimal, and the unmet needs of cancer survivors and their families require increased

attention and intervention (Hodgkinson et al., 2007).

A new model of care is being established at St Vincent's Hospital, in Sydney, designed to enhance the well-being of people following the completion of their cancer treatment. The quality improvement project involves three levels of intervention: 1) providing information booklets & appropriate resources, 2) constructing an individualised care plan, and 3) conducting a series of multi-disciplinary educational seminars.

The focus of these educational seminars includes: post-treatment coping and adjustment, returning to "normal life", countering depression and anxiety, managing treatment side-effects (such as fatigue, pain, sexual dysfunction), guidance with nutrition and exercise, managing work, finances, insurance and re-developing relationships and intimacy.

This program aims to enhance psychosocial adjustment and quality of life following cancer treatment compared to standard current practice. Qualitative feedback from both staff and patients will be utilised, in order to assess feasibility, utility, effectiveness and benefit of the program.

It is expected that additional knowledge, information, and support will reduce the burden of cancer survivorship, and increase access to appropriate resources and referrals. As this project is currently in progress, a mid-program review of research, theory, results, challenges involved, and current issues will be presented.

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### **An investigation of the outcomes of psycho-oncology service interventions**

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When someone is diagnosed with cancer, its impact extends beyond the physical effects of the disease. Cancer can cause considerable distress, impacting significantly on a person's quality of life psychologically, emotionally, socially, spiritually and functionally. The aim of this study is to investigate the effectiveness of a New Zealand psycho-oncology service in alleviating distress and improving quality of life for cancer patients and their family/whanau. This research will also attempt to identify moderating and mediating factors that might influence the effectiveness of psycho-oncology interventions. Twenty-five psycho-oncology service clients were recruited and matched for initial distress, age and gender, with twenty-five patients located in an area without access to the Psycho-Oncology Service. The intervention group completed validated scales measuring wellbeing and distress at 3 time points, (pre-therapy, post-therapy, 3-month follow-up). The control group also completed these measures following the same time line as the intervention group's therapy. A sample of psycho-oncology clients who showed least and most improvement over time were interviewed to examine potential factors influencing the effectiveness of their therapy. In keeping with the goals of the New Zealand Cancer Control Strategy, this study will provide much needed New Zealand evidence-based research regarding improving quality of life for those with cancer, their family and whanau. It will also provide valuable information that can be used by other DHBs in the implementation of similar services throughout the country. An overview of research to date and initial findings will be presented.



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### **Lessons from Spain: Feedback from the 10th IPOS Congress**

Juliet Ireland

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The 10th International Psycho-Oncology Society Congress was held in Madrid, Spain in June 2008. The theme was "Advancing Culturally Diverse Approaches in Psycho-Oncology and Palliative Care" which is a very relevant theme when thinking about our culturally diverse country. It was a large meeting with over 600 delegates from many professional groups including psychology, psychiatry, social work, nursing and academia. This talk will summarise the meeting, including pre-conference workshops, and discuss observations about Psycho-Oncological Approaches internationally.

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### **Unravelling every-day decision-making with phenomenology**

Kate Richardson

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Daily decision-making for people who have a non-curative terminal illness, such as cancer, has been given little attention by researchers in the past. To ameliorate this, a phenomenological study was conducted and ten participants receiving palliation were interviewed to inform nursing practice how much those everyday mundane decisions matter greatly. Decision-making is a complex and multi-faceted issue, and incredibly difficult to deconstruct but existential phenomenology offered a way to unravel respectfully the dialogue collected during interviews from this group of people. It gleaned richly nuanced and contextualised descriptions of participant's needs within a particular moment in time. Phenomenology is the study of essence and this research captured a snap-shot during a pivotal life moment with each of the participants. This study helped to make meaning and to contribute to a better practice by way of understanding phenomenological, hermeneutic and semiotic language.

Generating data from interviews can be called energetic reflections of the Self that presents the opportunity to know more of the Self. The information collected was about the subjective nature of integrity, spirituality and wholeness. True caring for the dying begins when I or you enter the world of another and we are truly present and humbled. Storytelling works in the sense of finding our place, understanding the world and making meaning, and appreciating the disclosive potential of the metaphor and symbol. The participant's stories became a stimulus and catalyst for feeling and learning about the complexity of issues surrounding daily decision-making and who holds the balance of power. The findings acknowledge that nurses need to reveal their caring focus and enable a person who is dying to have their independence and self-worth maximised where and when possible.

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### **Writing with photographs in the spirit of phenomenology with cancer patients**

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The researcher contests that photography is a companionable genre alongside narrative text when phenomenology is the research method. The hypothesis is that there is a viable link between phenomenological data analysis, and receiving and interpreting information from a digital image. It is believed that photographs produced as symbolic gestures and iconography together with narrative themes can communicate the lived experience by bringing an artistic dimension to the spirit and philosophy of phenomenology. Photography has had a convoluted history of struggle and equally is the controversy over using it for scientific data. The researcher believes that digital pictures can be used by communicating something to the viewer through both representation and iconic abstraction. Images signify that there is something out there in space and of having a “voice” through seeing and the chemical stillness and the drawing of the viewer into the photograph makes it different than that of any other textual medium or art form.

It is the making of pictures from the phenomena of light bouncing off things in front of the camera that causes a pulling together of objects and subjects, the lens, camera, light and colours into perpetual stillness. Visual art as an explanation and identification of symbols and iconology retrieved from interviews with research participants signifies a sense of being in the moment of someone’s life. The visual montages that the researcher makes must take part in telling a story and become part of a thematic centre. Staying faithful to the philosophy of phenomenology photographs as pieces of art-work, must stand along side the text as being scientific-thematic-intentions that describes the phenomenological lived experience of people living in a particular epoch. The researcher argues that we must let symbolic and iconic photographs stand up and speak out in the spirit and philosophy of phenomenology.

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### **Psycho-spiritual transitions in leukaemia**

Fay Davenport  
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Patients diagnosed with acute leukaemia provide particular and specific challenges for the many health professionals involved in their care. Diagnosis is often sudden, unexpected and as a result of generalised, non specific symptoms. Admission to hospital follows very soon after, as do a multitude of tests. Treatment may be complex, sophisticated, risky and frightening for the patient and family/friends. Admissions to hospital may be lengthy and complicated with the patient being significantly unwell, physically, emotionally and spiritually, and in protective isolation for periods of time.

Professionals may be greatly challenged by these patients. They may have to deal with anger, depression, manipulation, non communication and aggressiveness to name only a few possible psychological effects. The abilities of staff may involve the need to be creative, caring, to communicate effectively with the patient, family and colleagues. Staff may be stimulated to re-establish motivation, set appropriate goals for care and maintain the mood and spirits of all involved.

Philosophies, priorities, values and beliefs in life may be reassessed and redefined by patients during the illness experience. In this presentation I will consider some of the psycho-spiritual transitions that may occur during this period.

It is hoped that this presentation will stimulate discussion and dialogue with regard to the transitions patients with acute leukaemia may make and how the health professionals involved



might most effectively care for them.

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### **A validation of the Distress Thermometer in the New Zealand context**

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The Psycho-Oncology Service was established just over two years ago and is the first service of its kind to be developed in New Zealand. This presentation will provide a brief description of the Psycho-Oncology Service including its purpose and who is eligible to be referred.

A summary will also be provided of the findings of some recent local research which was undertaken with people diagnosed with cancer. This will include the problems that they report and the prevalence of symptoms of anxiety, depression and general distress. These findings indicate that emotional issues are significant problems for a large proportion of people with cancer. Distress experienced by family members and people with chronic disease will also be discussed. The findings of the investigation of the validity of the screening tool that is used by the Psycho-Oncology Service will also be reported.

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