

Welcome to Dunedin and to PONZ-8 Psychosocial Oncology New Zealand Conference 2009

SURVIVING CANCER: BODY, MIND AND SPIRIT

Keynote Abstracts

Associate Professor David Perez

David Perez is a medical oncologist at Dunedin Hospital and Associate Professor at the Otago Medical School. His research interests include communication with patients, quality of life assessment and clinical trials. In his role as Associate Dean for the Year 2 and 3 Programme at the Otago Medical School he is directly involved in fashioning a curriculum which promotes a partnership model for communication between the doctor and patient.

Putting the Patient at the Centre in Cancer Care

Patient centred medicine has been the touchstone of the medical consultation since late in the 20th century. This does not imply that patients dominate the consultation, rather a balance needs to be struck between the patient's needs and the medical imperatives. In most Western countries explicit information about a cancer diagnosis is now readily given but the style of delivery still needs refinement to reflect the sensibilities of individual patients. It is commonly assumed that all patients should be given information about prognosis but a significant minority prefer not to discuss prognosis and those that do prefer a mixture of realism, individualisation and preservation of hope. Denial of the prognosis can be a useful strategy in the adjustment process following diagnosis but other types of denial can be counter-productive and require expert intervention. The majority of patients wish to be involved in treatment choices but health professionals are poor judges of how much involvement the patient wants. In addition some patients make choices on the basis of inadequate information and others make highly subjective choices despite provision of adequate information. Patients like to be informed of expensive but unfunded treatments even when they can't or won't pay for such treatments. It is commonly assumed that quality of life should be a major consideration in cancer treatment decisions, however, some patients have a clear preference for quantity over quality and the issue of who is the best judge of.

[Podcast](#)



Dr Pam McGrath

Dr Pam McGrath, is a National Health and Medical Research Council (NHMRC) Senior Research Fellow who has established the International Program for Psycho-Social Health Research (IPP-SHR) at Central Queensland University (www.ipp-shr.cqu.edu.au). Her research examines psycho-social issues in relation to serious illness including work in bioethics, oncology, haematology, paediatrics, palliative care, regional and rural health, spirituality, Indigenous health and mental health. She has written five books, over one hundred and forty peer-reviewed articles and publishes the international quarterly review, *Psycho-Social Review*. She views research as an important instrument for translating insights about the human experience of serious illness into programs for health care service delivery and health policy development.



Hamish Holewa - due to circumstance, Hamish has very kindly agreed to give this paper and facilitate the Workshop

Hamish Holewa is the program manager of the International Program of Psycho-Social Health Research (IPP-SHR). His research interests include the development and implementation of new web based technologies to support collaborative research, qualitative methodologies, health economics, international health inequality and psycho-social supportive care health issues. Mr Holewa is currently a member of CQ University's Human Research Ethics Council, the International Research Promotion Council, and the editorial board of the *Austral-Asian Journal of Cancer*. He is also the developer and founder of QuadrantTM, an online collaborative research project management portal.

Psycho-oncology - Back to the future

Examples will be used from Dr McGrath's research to discuss the selection of agenda-setting issues, the process of obtaining funding and the finale of translating the research into practice, indicating what can be achieved and how far we have come. Current issues with regards to surviving cancer will be discussed.



Richard Egan

Richard Egan is Research & Teaching fellow in Preventive and Social Medicine, Dunedin School of Medicine, University of Otago. Working in the Cancer Society Social & Behavioural Research Unit, Richard teaches under and post-graduate health promotion; and his current research is examining psycho-social-spiritual support service referral practices. He has recently finished his PhD which examined spirituality in end-of-life care. Richard's Master thesis examined spirituality in New Zealand state education.

Spirituality: who cares?

This presentation considers spirituality in both the societal context and for those affected by cancer. The re-emergence of spirituality is examined, for behind the 'who cares?' question, is 'why care?'. The largest study examining spirituality in New Zealand hospice care will inform this discussion of some basic questions: what is spirituality?, what are our spiritual needs when living with cancer?, and how can such needs be addressed?

The author argues spirituality is a macro determinant of well-being and needs to be on the policy and healthcare professional education agendas; and most people with serious illness want their spiritual needs addressed, so assessing and addressing these needs ought to be the default position. Maori considerations and aspirations are essential regarding spirituality in New Zealand healthcare; and it will be further argued to not attend to them is ignoring Treaty of Waitangi responsibilities.

The re-emergence of spirituality in healthcare and society is controversial, but critically important, as it challenges ways and means of being and doing that at times leaves out the person. All those with cancer have the potential to be healed or made whole, whether they die of cancer or something else. Attending to spiritual care can help create conducive spaces for such healing.

Workshop Abstracts

1. Research and postgraduate study - the what, where and how?

Roz McKechnie

Research Coordinator Te Waipounamu Rural Health Research Unit, Dept of General Practice, University of Otago; Chairperson, Aotearoa NZ Palliative Care Foundation for Palliative Care Education and Research.

There are increasing pressures within the health work place that professionals up-skill by undertaking postgraduate education and research. Bearing in mind that many people won't have done any focused study since they graduated, they may not know where to begin, let alone finding the time and money to do it. Looking at university web sites can be confusing, especially if there are several options.

This workshop will discuss Postgraduate education and research including doing papers, Masters and PhD's. What is out there by way of support and how to access it? It will also include a question and answer session so think about the things you would like to discuss specific to your area of expertise. roz.mckechnie@otago.ac.nz

2. Demystifying working with children and young people

Kirsty Ross

Clinical Psychologist, Psycho-Oncology and Health Conditions Services, Massey University Psychology Clinic, Palmerston North.

This workshop will look at some common misperceptions about working with children, and discuss how working with children and young people (0-18 years) is different than working with adults, as well as provide some general principles about how to work effectively with children and young people. Tailoring interventions and therapy to the developmental stage and needs of the child will be a particular emphasis. Following this, findings from the literature about the psychosocial impact of cancer on children and young people will be presented, both children and young people who are

patients themselves, or who are family members of those with cancer. Finally, case studies of therapeutic inventions with children and young people affected by cancer (either as patients or family members) will be presented and discussed.

k.j.ross@massey.ac.nz

3. Doctors with cancer- the good the bad and the ugly

Tim Carey-Smith, Palliative Care Specialist; Sue Walthert, General Practitioner, David Perez, Consultant Medical Oncologist

Cancer by its very nature is ugly, but both good and bad can come from it. Health professionals are not immune to life-threatening disease, and when this occurs, unique relationships, dynamics and situations can develop between the health professional who is the patient, and the treating doctor.

Two doctors from different specialties will present their personal encounters with cancer. Their narratives will provide a catalyst for discussion around the positive and negative aspects that arise from being a doctor as well as a patient. Areas that will be highlighted include the relationship between doctor/patient and the treating doctor, communication with the treating doctor, availability of treatment and support, and coping with cancer as a doctor/patient.

It is hoped that participants at this workshop will pick up on the peculiar issues that being a doctor and a patient present, and add their own experiences and thoughts to the discussion.

4. Dislocation and invisibility: a workshop on relocation for specialist treatment

Hamish Holewa

International Program for Psycho-Social Health Research (IPP-SHR), Central Queensland University, Brisbane.

Relocating for specialist treatment is a challenge faced by many haematology patients who live outside the metropolitan area, as they are forced to leave the comfort of their homes to relocate to be nearer to the specialist care that is only available in major treatment centres. An expert on this topic, Dr Pam McGrath, a National Health and Medical Council Senior Research Fellow and Director of the International Program of Psycho-Social Health Research (IPP-SHR) at CQ University, has been invited to talk about this significant issue at the Psychosocial Oncology New Zealand Conference presently underway in Dunedin.

“Families who have to relocate are challenged by a multiplicity of issues including the need to leave immediately without preparation or knowledge of how long they will be away, problems with maintaining the family home in absentia and the distress of family separation,” reports Dr McGrath.

“It is common for those who have to relocate to experience disorientation and unfamiliarity with the metropolitan hospital and surroundings, travel and accommodation problems, financial impact and problems with work and education.”

Dr Pam McGrath, IPP-SHR, is presently conducting research funded by the Leukaemia and Blood Foundation of New Zealand that is examining specific relocation issues unique to the New Zealand context.

www.ipp-shr.cqu.edu.au

5. Psychological strategies in pain management

Malcolm Johnson

Department of Psychological Medicine, University of Auckland

Although the psychological context and nature of the disease responsible for cancer pain are often different to that of other painful conditions, the commonalities suggest that strategies useful for managing chronic benign pain might be helpful. In this workshop the literature on persistent pain is used to identify psychological processes that might also exacerbate cancer pain. Then, adaptations of psychological pain management strategies such as distraction, acceptance and relaxation that might be suitable for cancer pain sufferers are described. Workshop participants will have the opportunity to share strategies they have found helpful.

mh.johnson@auckland.ac.nz

6. Re-connecting with the body after diagnosis or treatment: a creative arts therapy approach

Amanda Levey, Psychologist and Arts Therapist. Burnett Clinic & Director, Masters of Arts in Arts Therapy Programme, Whitecliffe College of Arts and Design, Auckland

A diagnosis of an illness such as cancer and the ensuing medical interventions is a traumatic experience that can distance a person from their body, and negatively affect body image and self-esteem. This workshop will demonstrate how creative arts therapies can help a person to re-connect with their body and emotions as a way of processing and making meaning of their experiences. The creative arts therapies are a holistic approach to physical, emotional, and mental health that integrates the creative process with the expression of feelings, emotions, and personal images. This approach engages the whole person by utilizing movement, drama, music, writing and art-making as well as psychotherapeutic techniques, guided imagery, meditation and other mind/body-based therapies. This workshop will show how those who are diagnosed with cancer can be given a range of resources to assist them to access their own sense of what will improve their well-being and quality of life.

In the 1970s Carl O. Simonton and Stephanie Matthews-Simonton pioneered the use of visualizations and therapeutic techniques in their treatment of people with cancer. Anna Halprin is a dancer and educator who has innovated the use of movement and dance within the fields of expressive therapies and community. Through exploring the Simonton work she had a direct experience of drawing something unexplainable and unknown in her body. She chose to listen and make sense of that drawing, trusting that her body knew something that her mind didn't know. Anna had cancer and survived, and she has transformed that experience into a process for others to use.

Amanda Levey has trained extensively with Anna Halprin and is now working in conjunction with the New Zealand Breast Cancer Foundation and the Breast Cancer Aotearoa Coalition to design a creative therapies programme for women who have been diagnosed with breast cancer.

amandaL@whitecliffe.ac.nz

7. Integrating the bunker into mind, body and spirit - a radiation therapy and health professional perspective

Hazel Naser and Gay Dungey

Department Radiation Therapy, University of Otago, Wellington

This is an interactive workshop that will examine the impact of vicarious trauma or second hand-shock on oncology health professionals as a result of working with their patients. Strategies for managing or preventing vicarious trauma will be covered in order to prevent burnout. The workshop was developed out of the findings of a study conducted by Gay Dungey with student radiation therapists. These students indicated that their sense of identity and values had changed both positively and negatively as a result of working with cancer patients. This has highlighted the need for healthcare organisations/personnel to provide opportunities for peer support and clinical supervision to novice health professionals, in order to encourage them to develop effective coping

mechanisms that will sustain them in their professional practice.
hazel.neser@otago.ac.nz

Plenary Abstracts

1. Suffering and the “acceptability gap” – a conceptual synthesis.

Dr David MacKintosh

Medical Director, Otago Community Hospice, Dunedin

Despite acceptance that the relief of suffering is a primary goal of medicine a clinically useful conceptualisation of suffering remains elusive. The availability of such a definition is important to allow us to recognise that suffering exists or, possibly more importantly in clinical practice, to identify when suffering may not be present or intervention not required.

To be clinically useful a conceptualisation of suffering should be: intellectually accessible, generalisable and provide guidance with therapeutic intervention. One definition which claims to satisfy these conditions has been proposed – “Suffering is a consequence of self awareness and occurs when a person’s current state fails to match a state he or she is able to accept.” – the “acceptability gap”.

Based on the results of a qualitative study, reported in 2000, this conceptualisation shares much with related models in other areas of psychosocial enquiry, particularly the regulation of emotion and quality of life research; the “psychosocial transition”; the “Kalman gap”, the “response shift”, the “modal model” of emotion regulation and, more recently, “resilience therapy”. The common feature of these models is a recursive process appraisal resulting in individuals resetting their emotional responses and expectations with, hopefully, a consequent reduction in levels of distress. Despite their differing origins the above models, in fact, describe the same phenomenon – that of the experience of personal suffering and how individuals manage their suffering.

The concept of an “acceptability gap” in the description of suffering can be shown to satisfy the criteria for a clinical definition of suffering with particular regard to reaffirming the intensely personal nature of suffering, assisting with the identification of its presence or absence and assessing the need for and the outcome of intervention.

drdmac1@gmail.com

2. Transcending suffering: the survival of the family

Cynthia Ward, Manager/Nurse Specialist and Stephen Parkinson, Counsellor/Therapist
True Colours Charitable Trust, Hamilton

How do we as health professionals support the adjusting and reframe of family dynamics when they are living the cancer experience? This presentation we will explore the ongoing adaptations that parents, siblings and the sick child are forced to make for life to continue to have meaning for them. How families function with altered life plans will be examined, including the pain of shifting focus from wellness to the intense care and intimacy with the sick child and the challenge of remaining a family unit. What is our role as health professionals in supporting families to integrate their cancer experience into one that makes meaning; promoting quality of life and alleviating psychological suffering? The stressors on families who have a child with cancer are enormous. Feedback from families suggests that the care from health professionals has a significant role in their cancer experience. The quality of care can be pivotal to enhancing or hindering their process of finding

meaning as a family. How do we as health professionals support the child and family to make the adaptations and adjustments to a different way of 'being' whilst keeping the memory and spirit of their family culture alive throughout the journey? Strengthening relationships within the family and acknowledging the significance and influence of the family unit as they live with cancer is essential. Whilst we understand pain and grief are present for families who have a child living with cancer the care provided can help alleviate suffering and enhance meaning for the survival of the family. Case studies will be presented to demonstrate the challenges and unique creative responses that families use to continue meaningful relationships with each other and the sick child.

cynthia@truecolours.org.nz

3. The impact of premature menopause and fertility damage from cancer treatment

Sarah Hunter RN

Doctoral Candidate, University of Auckland

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 menopausal status and fertility. This presentation reports the findings of a qualitative study undertaken to explore the emotional and interpersonal impact of premature menopause and fertility damage.

Interview data was collected from 17 New Zealand women who were pre-menopausal prior to their diagnosis of cancer and primary treatment and identified fertility and menopause effects as important to them in the survivorship phase. Data was analysed using general inductive analysis techniques. The concept of liminality, and Chronic Sorrow Theory were used as aids to the interpretation and explanation of the data.

Four fundamental categories were identified that illustrated the participants' experiences of premature menopause and fertility damage from cancer treatment: Changes in the Balance of Choice and Control, Multiple Losses, Emotional Responses to Multiple Losses, and Changes in Perception of Self. Our understanding of these considerable impacts is crucial to the provision of patient-centered and effective survivorship care.

shun044@aucklanduni.ac.nz

4. Lifting the weight off breast cancer survivorship: the importance of progressive resistance training

Lynnette M Jones PhD¹, Debra L Waters PhD², Michael Legge PhD³

¹School of Physical Education, ²Department of Preventive and Social Medicine,

³Departments of Biochemistry and Pathology, University of Otago, Dunedin

Various forms of physical activity and exercise are recommended to breast cancer survivors to help offset the physiological and psychological dysfunction that follows treatment. Research to date, largely supports the use of aerobic type activities, such as walking and cycling, to improve fitness and perceived quality of life. While beneficial, these exercise modalities do not address the loss of muscle strength, particularly in the upper body, or changes in body composition that occur with adjuvant therapies. Progressive resistance training (PRT), or 'weight training', has been shown to improve body composition and increase muscular strength and endurance in other clinical populations, such as those with diabetes, post myocardial infarction patients, and the frail elderly. However, advocacy for PRT in cancer survivors is lacking and may be due to health professionals' unfamiliarity with this type of exercise, or concerns that PRT may exacerbate lymphoedema and/or increase the risk of musculoskeletal injury. Recent research demonstrates the effectiveness of PRT to increase exercise capacity, muscle mass and strength, decrease body fat, and improve quality of life.

Moreover, PRT does not appear to exacerbate lymphoedema; on the contrary, PRT can lower the incidence of symptomatic lymphoedema and improve upper body strength. While the evidence for the overall health benefits of resistance exercise is promising, more research is needed to determine specific movements and the optimal frequency, intensity, and total volume of exercise. There is also a need to investigate the optimal time to begin PRT relative to surgery and adjuvant therapy. This paper will present a review of the evidence to date on the use of PRT as an exercise modality for breast cancer survivors.

lynette.jones@otago.ac.nz

5. Meta-analysis of moderators of psycho-oncology therapy effectiveness: the poor can get richer

Dr Don Baken 1, Heather Heron 2, Dr Shane Harvey 3

1 Massey University Psycho-Oncology Service, 2 Massey University, 3 Director, Massey University Psychology Clinic

Funded by the Cancer Society of New Zealand

Initial reviews of psycho-oncology literature were supportive of the value of interventions in this field. However, more recent reviews have not been as encouraging. The small effect shown in these recent reviews seems curious given the proven nature of these interventions in other fields and the experiences of clinicians. In addition, a limitation of previous meta-analyses is that few have looked at the factors that might moderate the effect of psycho-oncology interventions.

This presentation will highlight some key findings of a recent meta-analysis and seek to link the findings with the design and implementation of psycho-oncology interventions. The analysis investigated the impact of a large range of potential moderators in the sociodemographic, psychological, medical and therapy areas by meta-analysis of controlled trials. Psychological outcomes measured were anxiety, depression, and general distress. An extensive search for both published and unpublished literature was undertaken, resulting in the examination of more than 3,000 records. The final dataset comprised 150 studies, including pseudo-random and naturalistic experimental designs, many unpublished studies and additional unpublished data provided by authors.

Main effects for therapy compared with untreated controls were medium to strong ($g = 0.52 - 0.70$) for clients with established distress before therapy. Explanations for some of the inconsistency in previous findings will be discussed. Some findings are consistent with what is already known and therefore provide further evidence to support what is already being done or further motivation to do what is at times difficult. Other findings are surprising and suggest further challenges and opportunities. Identification of moderating factors will allow the limited resources that are available to be used in the most beneficial way.

d.m.baken@massey.ac.nz

6. Childhood brain tumours and cognitive function

Sally Davis

Clinical Psychologist. Cancer Society Auckland Division

Brain tumours are the second most common form of childhood cancer. Medulloblastoma (MB) is a malignant posterior fossa brain tumour requiring surgery and radiotherapy while pilocytic astrocytoma (PA) is a benign posterior fossa brain tumour requiring surgery without radiotherapy. Both MB and PA occur predominantly during childhood. Research examining MB survivors beyond seven years post-treatment is rare. Similarly, research available on the adaptive functioning, in particular coping and quality of life, experienced by survivors of posterior fossa tumours is limited.

This study observed the long-term neuropsychological and adaptive functioning outcomes of MB and PA survivors. Using a NZ sample of MB and PA survivors, comparisons were made between those who had radiotherapy post-surgery (MB; n=20) and those who had surgery alone (PA; n=19) to help identify the impact of radiotherapy on neuropsychological outcome and adaptive functioning. A control group demographically matched to the MB participants helped determine the overall impact of these posterior fossa tumours. Treatment variables and late effects were also examined. Radiotherapy was found to have a profound long-term impact on the neuropsychological functioning of MB survivors; particularly in the areas of memory, attention, information processing speed, and executive functioning. The PA group, who had surgery without radiotherapy, also displayed deficits in these areas of neuropsychological functioning although to a lesser extent. Neuropsychological deficits did not, however, occur in the context of altered coping or reduced quality of life, except in the area of 'Learning'. Older age at diagnosis and increased time since surgery were related to better performance on neuropsychological tasks, while increased total number of treatment complications and late effects had a negative impact on neuropsychological performance. These findings are of relevance to rehabilitative therapy, and identifying expected deficit areas, and thereby allowing these to be targeted to improve level of functioning and quality of life.

sdavis@akcansoc.org.nz

7. Facing the inescapable and sustaining hope: reflections on transition to Hospice palliative care

Jacqui Bowden-Tucker RN
Hospice Marlborough

As health professionals working within cancer care, sometimes we are on the receiving end of that care either through a personal encounter with cancer or in sharing the cancer journey of a close friend or family member. These experiences in themselves can reveal unique insights and stimulate reflection upon the healthcare system of which we, in our professional roles, are part and has been the case for the author.

This paper chronicles one week in which the author 'journeyed' alongside her brother, as he transitioned to hospice palliative care five weeks prior to his death in February 2008. From triangulation of direct observation within the transition period, personal communication and patient narrative by way of personal diary, the author offers unique perspectives. These perspectives illustrate the increasing importance maintaining hope played in enabling his ongoing engagement with living whilst transcending the inescapable reality of terminal cancer. Within one week multiple encounters with care professionals across primary health, emergency department, community nursing and hospice outpatient settings both supported and challenged the maintenance of hope.

Current literature on the concept of hope in terminal illness from both patient and healthcare professional(s) perspective is also considered and provides further depth to the discussion and insights presented.

This paper endeavours to act as a stimulus for ongoing discussion and reflection within our healthcare professions as to how we individually and collectively conceptualise hope and our responsibilities in developing environments and interventions that promote hope and ease suffering for patients and their families in any care setting (Buckley and Herth, 2004).

acqui_bowden-tucker@nzf.salvationarmy.org

8. Does empathy and stigma differ among patients and caregivers with smoking or non-smoking related illnesses?

Freya Hansen, B.A.(Hons.), M.N., R.N

University of Manitoba, Winnipeg, Canada

In Canada and the United States, changing attitudes towards cigarette smoking have resulted in a social stigma or 'spoiled identity' facing smokers and those with smoking-related illnesses such as lung cancer and Chronic Obstructive Pulmonary Disease (COPD). Many patients rely on family or other caregivers for their day-to-day care and empathic behavior is one essential component of effective communication to facilitate the caregiving relationship. This exploratory study examined whether there is an association between caregiver and patient stigma and empathic behaviour among patient / caregiver dyads with smoking-related illnesses compared to a colorectal cancer control group. Thirty-four patients (19 diagnosed with a smoking-related illness and 15 diagnosed with colorectal cancer) along with their caregivers were recruited to participate in this study. The four empathic behaviour scales utilized demonstrated good reliability with both diagnostic groups; however, the stigma scale used was shown to be reliable only with the colorectal cancer group and had poor reliability in the smoking-related illness group. There were no differences found in either patient or caregiver stigma between diagnostic groups but there was a trend for patients to report more stigma than caregivers. Younger patients reported more stigma and when patients and caregivers reported no preference for religion, they reported more stigma. Empathic behavior was found to be positively related to patient and caregiver education, patient income, and negatively related to patient and caregiver smoking history. Patients diagnosed with smoking-related illnesses viewed their caregivers as less empathic than patients in the colorectal cancer group. Patients with a stigmatized illness and their caregivers may ultimately benefit from this research as empathic behavior has been shown to be potentially modifiable and interventions may be developed to ameliorate or prevent any identified detrimental effects of stigma that may impact optimal empathic behavior.

fehansen@mts.net

9. The use of rituals as a form of support and comfort: "You can't do that - Can you?"

Margaret Alve*, Sue Bannister, Sally Davis

Child Cancer Foundation – Family Support Team, Wellington

"Even before people could write, rituals helped people face the unexpected changes of life", Doka (2000). A ritual is an intentional act, thought or spoken expression intended to bring meaning into seeming meaninglessness, hope into hopelessness, order into chaos, and bring significant connection with others. In this paper we will cover what helps people make meaning of grief, loss, change or bereavement and explore ways to honour the difficult and painful experiences and integrate them into an authentic way of being.

As society has moved away from traditional spiritual practices, there is a desire and freedom to find and create new ways to mark important life experiences. We will explore historical and contemporary approaches to helping people create sacred spaces, including how the younger generation use social networking tools such as Bebo, MySpace and Facebook. We will share rituals that families and the Child Cancer Foundation team have used, and provide opportunities for participants to share ideas.

The team will also look at the use of rituals as a therapeutic tool, focussing on the concepts of listening, hope questions and mindfulness to explore and validate the rituals or spirituality the client has used in the past. This process helps invite new conversations and supports clients in discovering meaningful rituals that fit their present circumstance.

Participants will leave with a deeper appreciation of the use of ritual, as well as new strategies, practical ideas and resources to use and adapt for use with clients in their own environment.
malve@childcancer.org.nz

10. A Steinian approach to an empathic understanding in the face of cancer

Kate Richardson

PhD Student, School of Nursing, University of Deakin, Melbourne

The caring of another human being is never done in isolation nor is it often a meritorious act. It is however, the conscious and intuitive effort that blends touch, presence, thought and belief together despite differences, traditions and mores between the self and others. This paper was inspired by the work of Edith Stein. As a philosopher and phenomenologist, Stein considered herself a German woman of Jewish descent who converted to Catholicism. She is reported to be the first German female philosopher and was a nurse at the Front in World War I and then at the age of forty-two went on to become a Carmelite nun. Finally Stein gave with her life along with thousands of others who died on August 9, 1942 in Auschwitz. This paper draws on the Steinian approach to caring, especially that of empathy and the human person, reason, faith and hope.

In the context of the author's current research on hope in patients with terminal cancer and the hopes of their clinicians it became necessary to consider the role that empathy plays. What does it mean when clinicians are faced with the hopes of others that may not coincide with their own notion of hoping? Empathy is a means to the knowledge of humanness thus the knowledge of human nature can enliven and encourage empathy. Stein believes that it is possible to "empathize" or "sense in" another person even though one does not experience primordially what another undergoes. Empathy can only be the non-primordial experience which announces a primordial one and because each person has their own hoping level these must be respected and guarded in an empathic not sympathetic manner. Being empathic to the hopes, dreams and desires of others enables people to potentialize their individual psychophysical being and rebalance them.

kate.richardson@otagodhb.govt.nz

11. Survive to thrive: the preliminary results of a post treatment intervention, to facilitate emotional and spiritual transition, for cancer patients and their families.

Jane Currie 1. and Kieren Faull 2

1 CEO of Health Journeys Foundation, 2 Psychologist & Clinical Development Facilitator, QE Health, Rotorua

This pilot, run by Health Journeys (Hamilton) in conjunction with QE Health (Rotorua), since April 2009 utilises the Health Change Process Theory, is based in Hamilton for cancer patients post treatment. The aim is to facilitate the transition from cancer patient and the experience of trauma to reintegration, normalcy and full holistic health. Following an outline of the holistic theoretical basis and an overview of the workshop-type group intervention, the quantitative and qualitative outcomes of a pilot program will be presented.

The presentation will conclude with a discussion of the meaning of these results and Health Journeys future plans.

jane@healthjourneys.org.nz

kieren.faull@qehealth.co.nz

12. Understanding the issues faced by cancer survivors in New Zealand

Penny Hayward 1, Dr Don Baken 2, Dr Christine Stephens 3.

1Massey University, 2Massey University Psycho-Oncology Service, 3Massey University

International research on cancer survivorship has started to identify a range of issues that affect cancer survivors physically, mentally, emotionally and spiritually from the date of diagnosis, throughout treatment and for the rest of their lives. The quality of life and well-being cancer survivors experience depends upon many interacting factors including the type of cancer, type of treatment, health utilisation, social support, employment status, locus of control, ethnicity and socio-economic status. However, it is questionable whether the same results could be ascribed to New Zealand cancer survivors given our particular cultural makeup.

The objective of this study is to investigate the significance of some of these interacting factors upon the quality of life, health and support needs of cancer survivors in New Zealand when compared to the rest of the population. Of further interest is whether ethnicity might affect the outcomes. It is hoped that the information provided by this study will help to inform future policy and interventions for cancer survivors.

This presentation will discuss data analysed from the 2008 Health Work and Retirement Survey for which over 3000 participants ranging in age from 57-72 were randomly selected from the New Zealand population (including an over-sample of Maori). This is an age group which carries both the high burden of a cancer diagnosis yet also has several years of potentially active participation in society to come. 2495 participants responded and 1025 of the respondents identified themselves as being Maori; 279 participants reported having cancer and 102 of this group were Maori. The analysis makes comparisons between cancer survivors and a control group of participants without cancer on factors such as health care utilisation, social support and work status. Further comparisons will be made using ethnicity as a moderating variable.

penelopeh@xtra.co.nz

13. Upload, download, unload: LifeBloodLIVE – an online forum for haematology patients

Amy Munro*1, Christine Kerr*2, Lisa Speed3, Debbie Moore1

1Leukaemia & Blood Foundation, Auckland, 2Leukaemia & Blood Foundation, Christchurch,

3Leukaemia & Blood Foundation, Wellington

Introduction: Imagine you have just been diagnosed with leukaemia. You may never have heard of this type of cancer, let alone know the spelling. But that won't stop you, or your family, from googling it. Just as health professionals search the internet for information, so do patients. In this technological age, patients use this medium to find both instant answers and information, particularly experiential information which describes the experiences of fellow cancer patients¹.

Background: Research has shown that treatment preferences are strongly influenced by fears, misconceptions and anecdotes rather than by population-based information¹. Helft et al have shown that approximately 30% of cancer patients use the internet to obtain cancer information²; however, only 30% of these patients discuss their findings with their doctors². Experiential information is found in case studies, opinions, stories, peer mentoring, online forums etc. This information can help normalise patients' experiences, address isolation issues and portray the treatment and recovery experience, thereby enhancing self-efficacy for coping and promoting involvement in care¹.

Methods: To address the need for a New Zealand-based internet resource, the Leukaemia & Blood Foundation developed LifeBloodLIVE, an online forum for patients to share experiences, find links to

reputable websites and gain accurate information. Users are encouraged to keep a degree of anonymity and candour, and the site is moderated daily for inaccuracies by specialist haematology nurses.

Results: Launched in 2008, the site now has more than 160 active users from diverse backgrounds, locations and haematology conditions, especially benefiting those in rural communities.

Conclusion: Providing patients with current and easily accessible information and support is crucial. Use of the internet medium communicates with people where they are seeking information and complements traditional communication methods of conversations and written materials. By acknowledging and facilitating the exchange of experiential information in a non-threatening environment, patients are assisted in their cancer journey.

1. Rini et al. Peer Monitoring and Survivors' Stories for Cancer patients: Positive Effects and Some Cautionary Notes. JCO, 25:1 2007.
2. Helft et al. Use of the Internet to Obtain Cancer Information Among Cancer Patients at an Urban County Hospital. JCO, 23:22 2005.

14. Insights from play: findings on procedural distress for children surviving treatments for leukaemia

Dr Pam McGrath

NH&MRC Senior Research Fellow; Director, International Program of Psycho-Social Health Research (IPP-SHR); Central Queensland University, Brisbane

Children diagnosed with leukaemia have lengthy and invasive treatment protocols and thus are vulnerable to repeated exposure to distressing hospital experiences. In order to understand the impact of intensive hospital treatments it is necessary to have comparative information on healthy peers who have not been exposed to such treatment experiences. This presentation explores findings from a longitudinal study on paediatric leukaemia that compares data from recorded play sessions with two groups of children: healthy children at a local preschool; and children undergoing treatment for leukaemia.

The findings from the data collected from the former group indicate that children who are not exposed to intensive hospital treatments have a naïve, joyous curiosity about medical equipment. They are unsophisticated in their understanding of the purpose of such equipment and make quite erroneous guesses at its use. The indications are that where children have not been traumatized by a medical experience they integrate medical equipment into their play without hesitation. By comparison, the findings on the children treated for leukaemia indicate a strong approach/avoidance response to medical equipment, with children either playing obsessively for long periods with the equipment or strongly avoiding any contact with it. The children with leukaemia have a sophisticated idea of the purpose of the medical equipment and can describe the equipment using appropriate clinical language.

The findings point to the distressing emotional sequelae associated with invasive medical procedures for children undergoing treatment for leukaemia as revealed by their responses to medical play. Such responses, obsessive play and avoidance, resonate with the literature on posttraumatic stress and are dramatically different to those of children not exposed to such treatment experiences. The study highlights the need to respond therapeutically to such procedural distress and demonstrates the efficacy of play as a medium for communication with child patients about issues of this nature.

pam_mcgrath@bigpond.com
www.ipp-shr.cqu.edu.au

15. CANCER CONNECT – a peer support service for people living with cancer

Dr Rae Noble-Adams*, Liz Horn, Meg Biggs
Canterbury/West Coast Division of the Cancer Society of New Zealand, Christchurch

It has long been recognized that people who have cancer can benefit from talking to other people who themselves have been faced with a diagnosis of cancer. This support can be a valuable adjunct to their medical care. An individual who has personally experienced cancer is uniquely able to understand the feelings of someone else in a similar situation.

The Cancer Society of New Zealand Cancer Connect Service, run by the Canterbury/West Coast Division of the Cancer Society of NZ, provides this personal interaction through matching people living with cancer with carefully selected and trained volunteers who have also had their own lives affected by cancer.

Since its inception in 2005, over 600 cancer patients or their care-givers have been matched by qualified Cancer Connect Coordinators, throughout New Zealand. These clients accessed the service for various reasons, including support and advice on the practical, social, family or psychological impacts of their cancer diagnosis and treatment.

This presentation will describe the history and development of the service in New Zealand, and will discuss as an example, the number of successful Cancer Connect matches during the year July 2008-July 2009 (n=156). Included will be the clients; gender, age, cancer type, time from diagnosis, treatment, marital status/number of children, geographical region, and most importantly, their reason for referral.

This baseline data is Part I of a two-part audit/research project which aims to discover any gaps in the service and to identify satisfaction with the service from the clients, volunteers and referrers perspectives.

rae@canty.cancernz.org.nz

16. Re-fuelling for palliative care nurses – a recent look at compassion fatigue

Jane Rollings, RN, PGCert Palliative Care
Clinical Nurse Manager, Nurse Maude Hospice Palliative Care Service, Christchurch

Caring is inherent in nursing and in nurses – it is the foundation of the profession (Thomas, Finch, Schoenhofer & Green, 2004). To be able to care is a privilege and provides much satisfaction for those who have chosen nursing as their career. However, there is also a cost to caring. Compassion fatigue is one such cost (Tehrani, 2007). The impact of continuing to care for those suffering and traumatized can lead to compassion fatigue or other identified syndromes such as burnout, vicarious traumatization or secondary stress disorder to name but a few (Abendroth & Flannery, 2006; Sabo, 2008; Sinclair & Hamill, 2007). My focus as a nurse manager in a hospice is the care of my staff – if they are not at their best they don't give their best and become vulnerable to the stresses and strains that they face in their work of caring for the dying. In this presentation I would like to talk about what compassion fatigue is and how we can avoid it and heal it. I will also present results of a recent literature review focusing on whether compassion fatigue actually is a real problem for hospice nurses.

janer@nursemaude.org.nz

17. The voice of experience: results from New Zealand's first national cancer care survey

Inga O'Brien, Wayne Naylor, Emma Britton
Cancer Control Council of New Zealand, Wellington

Aim: This project aims to establish, for the first time in New Zealand, how people with cancer experience their care.

Method: In mid 2009, the Cancer Control Council of New Zealand sent a postal survey to a random sample of 3525 adults, who had received outpatient cancer care between October 2008 and March 2009. In order to achieve as high a return rate as possible, the initial postal survey was followed by a reminder postcard and a second survey. Identified participants also had the option of completing the survey online at a secure website. Potential respondents were selected from eight cancer treatment facilities across New Zealand. The survey, an internationally recognised NRC Picker questionnaire, addressed 8 dimensions of care that impact on an overall 'experience of care' measure. An anticipated response rate of 50-60% was based on the response to similar surveys in other countries. Ethical approval was granted for this project.

Results: Response rates are on track for reaching a greater than 65% return rate. Analysis of the data will be undertaken in September 2009. The data will be weighted and analysed to assess the overall scores and distribution of scores in relation to key inequality and care dimension drivers. The relevant national and regional level results will be reported during the conference presentation.

Conclusion: The results from this survey will be used to inform and advise policy-makers and health services on 1) how a sample of cancer patients currently experience the healthcare system and 2) how services could evolve to reduce inequalities and better meet patient (and family) needs. This first survey 'snapshot' provides important baseline data. It is expected that this work will develop into an ongoing monitoring programme, which will be able to provide valuable information as to how system changes affect the cancer patient experience over time.

inga_o'brien@cancercontrolcouncil.govt.nz

18. Emotional and spiritual transition through cancer - The Journey

Helen Brown MD
General Practitioner

We all have our own journeys in this life. For some of us it will be cancer. This journey may teach us about death, life and happiness.

How do we survive the emotional journey? How do we become happy?

My talk will cover some of my own journey, research and a range of other people's experiences. We will look at how to let go of the grief you suffer when you get cancer and moving on in an emotional and spiritual way to become a much happier person

When you get cancer you lose your illusions of invincibility, you lose your physical confidence; your work, your relationships change. Your life changes.
Your views on life will change, what might have seemed so important before is not now.

The journey is learning to let go, change yourself, as now you have cancer perhaps something was not working before. This can be hard to look at.

Now you face death- one of the things we all face, some sooner than others. Often it is about learning to live in this moment, and be truly present. We do not know what will happen tomorrow but we can live today.

How do we get to this point? It involves reviewing the way you think. We look at mindfulness meditation which involves recognizing your emotions and sitting with them. Forgiveness, gratitude and thinking more positively, letting go of judgment, using constructive emotions- all these will help to change the way you think, make you more positive and happy.

Positive emotions do affect our bodies as do negative emotions, increasing your positive emotions will help you to become well, and cope with anything.

Letting go of old emotions will help you to be happy in this moment right now.

A lot of people who get cancer say they are glad they got their lives are so much happier. We can all change ourselves.

helen@canlive.org

www.canlive.org.nz

19. Identifying priorities for psycho-social-spiritual cancer research in New Zealand: perspectives from the Cancer Society of New Zealand Support Services

Richard Egan 1, Qa-t-a Amun 2, Susan Sutcliffe 3

1University of Otago, Preventive & Social Medicine; 2University of Otago, Preventive & Social Medicine; 3Cancer Society of New Zealand

Holistic approaches are recommended across the cancer care continuum. The cancer burden includes significant psycho-social-spiritual issues, as is evident in this research, the literature, policies and guidelines. Research is useful to help inform and evaluate support services. The Cancer Society of New Zealand (CSNZ) provides an important and wide range of support services across the country and through its six Divisions. In partnership with CSNZ, the University of Otago's Cancer Society Social & Behavioural Research Unit (SBRU) sought the voice of the support service 'experts', the people doing the work with consumers, and; canvassed the literature regarding consumer needs. That is, the aim of this research was to determine the psycho-social-spiritual (PSS) research priorities of CSNZ support staff.

Three data sources contributed towards the recommendations from this research. A rapid review of the literature was conducted to summarise the current national and international literature on the psychosocial and spiritual needs of cancer patients, their families, whanau or carers. Qualitative methods were used to investigate the research priorities of CSNZ support staff. Focus groups and key informant interviews were employed to understand the views of support staff from across all six Divisions and key National Office staff. While specific detail within each area varied, the three sources prioritized the following three themes: referral issues, consumer needs and evaluation needs.

This presentation will consider the range of psycho-social-spiritual issues, discuss the research findings and subsequent research directions.

richard.egan@otago.ac.nz

20. Making the case for using dream talk in cancer care

Andu lordache

PhD Candidate, Department of Psychology, University of Auckland

The International Psycho-Oncology Association has recently endorsed “Distress” as the sixth vital sign in the case presentation of cancer patients. Research within the dream psychology field has shown that content of dreams often reflects current waking concerns. Such findings suggest that dream reports may be useful in healthcare both to assess distress and as an outcome measure for treatment of distress. Moreover, it can be argued that dreaming may have a therapeutic function, as evidenced by studies of people facing a personal crisis (i.e. divorce, bereavement) which have found that dreams can facilitate emotional regulation and help to master overwhelming stimuli.

Recent trends in palliative care also indicate that encouraging patients to pay attention to their own dreams may be meaningful experiences, helping to relieve suffering even as the disease continues to progress. Communication processes between the cared and the carers may be improved by dream talk - a non-invasive approach that generates a safe environment for people to express their existential concerns and may contribute to reducing feelings of isolation.

Dream assessment and intervention are not currently part of the mainstream medical practice. Alternative therapies have been using dream work extensively but they are rarely research informed and efficacy testing is overdue. In an attempt to address this lack of evidence-based research, a pilot project is currently in progress at hospices in Auckland, aiming to explore how dreams can be employed to improve quality of care.

Dream reports are being collected from patients via retrospective estimates and daily records, with a view to identify common themes and patterns of dreaming and meaning making. The Missoula-Vitas Quality of Life index is administered before and after dream recordings in order to assess correlations between dreaming characteristics and quality of life dimensions, as well as impact of dream recording/telling on wellbeing.

s.iordache@auckland.ac.nz

21. Bearing witness to suffering – letting go of control

Dr Anna Holmes

PhD Candidate Department of Bioethics, University of Otago

Medical Officer, Otago Community Hospice, Dunedin

Care of the whole person demands bearing witness to suffering, in ways that are often demanding for clinical carers. This comes about because good care needs compassionate empathy with the patient at the same time as achieving appropriate clinical distance.

As patients move towards death there is also a process of letting go of control by both patient and clinician. Accommodation with death and letting go of life are spiritual issues that touch into the sacred in medicine.

These matters will be discussed in the light of interviews with 22 General Practitioners as research for a PhD on Spiritual Issues in General Practice.

jd.adholmes@xtra.co.nz