

# Optimising psychosocial care through clinical and research excellence

**OZPOS and PoCoG Psycho-oncology Professional Day  
8 November 2010**

Final Report

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and the PoCoG Executive Office

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## 1. Executive summary

The second OZPOS and PoCoG Psycho-oncology Professional day was held on Monday 8 November 2010 at the Melbourne Convention and Exhibition Centre, as a satellite event to the Clinical Oncological Society of Australia's (COSA) 37th Annual Scientific Meeting (ASM). The focus of the second Psycho-oncology Professional day was aspects of survivorship care and complex clinical cases in psycho-oncology.

The Professional Day was jointly funded by COSA and PoCoG. PoCoG received funding for this event from the Australian Government through Cancer Australia.

120 individuals registered through ASN conferences in conjunction with their registration for the COSA ASM and 105 attended the Psycho-oncology Professional Day. The attendees were predominantly Australian psychosocial researchers and clinicians, nurses, social workers, oncologists, health professionals and others with an interest in psycho-oncology.

The program comprised a plenary session, three research sessions, three workshop sessions and a panel discussion session. The discussion panel was chaired by the international guest A/Prof. Matthew J. Loscalzo whose participation in the Professional Day was generously sponsored by COSA.

The professional day overall was very highly regarded with over 97% of participants rating it as either very good or excellent. Most respondents thought that it was important to have an opportunity to present research outside of the COSA ASM, attend clinical skills workshops, perhaps highlighting the lack of such opportunities in general.

The second OZPOS and PoCoG Psycho-oncology Professional Day was once again successful in providing a dedicated forum for the excellent psycho-oncology research being conducted in Australia and creating an opportunity for researchers and clinicians to interact and exchange ideas. The event successfully engaged junior researchers by giving them an opportunity to present and receive feedback about their work and establish more formal links with clinicians and researchers. The event also gave them the opportunity of being involved in the planning of the scientific program and taking on roles of session chairs.

## 2. Introduction

The second OZPOS and PoCoG Psycho-oncology Professional day was held on Monday 8 November 2010 at the Melbourne Convention and Exhibition Centre, as a satellite event to the Clinical Oncological Society of Australia's (COSA) 37th Annual Scientific Meeting (ASM). The Professional Day aimed to bring together researchers and clinicians working in psycho-oncology to consider initiatives to promote quality cancer care and to share ideas so that research is clinically meaningful. It also aimed to provide an opportunity for clinicians to gain access to innovative research ideas. The focus of the second Psycho-oncology Professional day was aspects of survivorship care and complex clinical cases in psycho-oncology.

The Professional Day was jointly funded by COSA and PoCoG. PoCoG received funding for this event from the Australian Government through Cancer Australia.

## 3. Participants

120 individuals registered through ASN conferences in conjunction with their registration for the COSA ASM and 105 attended the Psycho-oncology Professional Day. The attendees were predominantly Australian psychosocial researchers and clinicians, nurses, social workers, oncologists, health professionals and others with an interest in psycho-oncology.

## 4. Professional Day Summary

The Professional Day program comprised a plenary session, three research sessions, three workshop sessions and a panel discussion session.

### 4.1. Plenary session

The plenary session entitled *Cancer Survivorship: key issues in research and clinical care* outlined different aspects of cancer survivorship including issues for carers and their families, cognitive issues for cancer survivors as well as summarising systematic approaches to cancer survivorship. The session comprised three presentations given by Prof. Afaf Girigs, A/Prof. Janette Vardy and A/Prof. Michael Jefford.

### 4.2. Research presentations

Fifteen oral presentations for three research sessions were selected from among poster abstracts submitted under the Supportive Care category to the COSA ASM. The sessions were chaired by early career clinicians and researchers in the area of psycho-oncology in order to give them the opportunity to gain experience in this role. In addition, the international guest A/Prof. Matt Loscalzo acted as discussant for session 1. The presentations were grouped into three themed sessions as follows:

- Vulnerable groups affected by cancer chaired by Dr Laura Kirsten
- What's hot – Emerging new research in psycho-oncology chaired by Dr Nadine Kasparian
- Psycho-oncology implementation chaired by Dr Jaklin Elliott

Details of the presentations in this session are included in the Appendix.

### 4.3. Clinical workshops

The Psycho-oncology Professional Day hosted three clinical workshops which were designed and conducted by PoCoG and OZPOS members with extensive clinical experience in psycho-oncology:

- Mindfulness in psycho-oncology (introductory session) – Facilitator Dr Elizabeth Foley
- Mindfulness: Clinical practicum - Facilitator Dr Elizabeth Foley

- Helping parents with cancer to talk to their children – Facilitator: A/Prof. Jane Turner

Workshop registrations were carried out using the EventsPro software package. Workshop outlines and information about presenters are included in the Appendix.

#### 4.4. Panel discussion

A panel discussion entitled *Challenges at the coalface: responding to complex clinical problems*, chaired by the international guest A/Prof. Matt Loscalzo, provided the opportunity for participants to hear clinical experts from a variety of disciplines describe their approaches to challenging clinical cases that were submitted as case vignettes by members of PoCoG and OZPOS for this session. The panel members were Dr Jane Fletcher (Clinical Psychologist), Prof. Brian Kelly (Psychiatrist), Dr Carrie Lethborg (Social Worker).

Panel discussion case vignettes and information about the panellists are included in the Appendix.

## 5. Professional Day evaluation

The registrants of the Psycho-oncology Professional Day were invited to participate in an online follow-up survey to determine the satisfaction of the attendees and the direction of future psycho-oncology professional meetings. Of the 120 registrants, 35 individuals (29%) participated in the feedback survey. Six of these participants did not complete the questionnaire. Twenty-three of the respondents indicated that they were members of COSA and of those 10 indicated membership of OZPOS, three indicated membership of OSWA, two – membership of CNSA and one – membership of MOGA. Twenty respondents indicated membership of PoCoG with 16 also indicating COSA membership. About a third of the respondents indicated that their primary occupation was in research, a third as primarily clinical and a third as both researcher and clinician. More than half of the respondents indicated their professional discipline to be psychology/behavioural science. Other represented disciplines were medicine, nursing and social work.

The professional day overall was very highly regarded with over 97% of participants rating it as either very good or excellent. Other general aspect of the workshop: timing in association with the COSA ASM, quality and relevance of sessions and the overall idea and purpose were rated similarly well. Most respondents thought that it was important to have an opportunity to present research outside of the COSA ASM, attend clinical skills workshops, perhaps highlighting the lack of such opportunities in general.

Suggestions for additions/improvements to the professional day included holding the event closer in time to the OSWA meeting to enable social workers to benefit from both COSA and the Psycho-oncology Professional Day and to hold research training workshops; The respondents also suggested a broader focus which would be more inclusive of other professions providing psychosocial support. The concurrence of clinical and research sessions posed a problem for some as this prevented them from being able to attend both. There was a call for workshops for researchers as well as clinicians. Some respondents expressed a need for recognition of the event as a professional development activity.

Table 1 shows topics for future research sessions and workshops as suggested by the respondents. Cost and time were perceived to be barriers to attendance, especially for clinicians. Despite this, two-thirds of the respondents indicate they would be willing to contribute up to \$100 as a registration cost.

**Table 1. Session topics suggested for future Psycho-oncology Professional Days.**

Panel discussion topics: Euthanasia, indigenous groups
Topics that would involve clinicians to participate.
Psycho-oncology case studies again - this was so useful, and a great CPD session. Clinical workshops on specific therapeutic techniques, e.g. MAPS etc.
These days are great for hands on experience - workshops and hearing about 'how to' for both clinical

and research.
Psychometrics, measurement issues in psycho-oncology, key concepts/instruments
Management strategies for psychological distress
Cognitive Behavioural Therapy
Addressing psycho-social issues for people and their families where this is no cure e.g. mesothelioma
Impact of a hereditary predisposition to cancer
Survivorship-specific issues how these can be effectively addressed
Presentations on carers or bereavement.
New research techniques
New technologies
Discussing prognosis and hope

Summaries of evaluation of individual sessions are provided in sections 4.1 – 4.4 below. Respondents were asked to rate various aspects of each session. These included:

Session format	Educational/informative value
Session length	Quality of facilitators/panellists/discussants
Session relevance	Quality of materials provided
Audience engagement	Overall quality

### 5.1. Plenary session

Over 90% of respondents rated the plenary session either very good or excellent on all aspects with educational value tending to be rated slightly lower than the other aspects. Few comments were offered but reflected general satisfaction with the session.

### 5.2. Research presentations

#### Vulnerable groups affected by cancer

Session length, relevance and informative/educational value were all rated excellent or very good by 93% or more participants. The format and the value of the discussant in the session were rated lower. Participants felt that more time should have been given to questions and discussion and that the discussant could have stimulated more debate. However the participants also acknowledged time limitations as a factor contributing to these issues.

#### What's hot – emerging new research in psycho-oncology

The 10 respondents who attended this session rated all aspects as either excellent or very good. The participants thought that the session was of high quality but that there was insufficient time to discuss the content of the presentations in more detail.

#### Psycho-oncology implementation

This session was well received with all respondents rating all aspects of the session as either good or excellent

### 5.3. Clinical Workshops

#### Mindfulness in oncology

Of the 30 registrants for this workshop 7 responded to the survey. All respondents rated the format and length as well the facilitator as either very good or excellent. Clinical relevance, pre-reading/handout material and educational value were rated somewhat lower.

#### Mindfulness: Clinical practicum

16 registrations were received for this workshop. This session was well regarded by the 5 survey respondents who attended it most of whom rated all aspects of the session as either very good or excellent.

#### Helping parents with cancer talk to their children

The 11 respondents who attended this workshop rated most aspects as either very good or excellent. There was somewhat less satisfaction with audience engagement but it was unclear from the few comments that were offered what was the reason for this evaluation. This workshop received 25 registrations.

### 5.4. Panel Discussion

This session received the most favourable comments from the survey respondents who saw the session as a highlight of the day, very enjoyable, educational and vibrant. Most ranked the overall format of the session as either very good or excellent and most indicated that they would like a similar session included in the professional day program in the future.

The aspects of educational/informative value and encouraging researcher-clinician communication were rated comparatively lower than other aspects of the session. None of the respondents offered comments which would explain this perception. Suggestions for improvement included a wider representation of disciplines on the panel, inclusion of non-adult focused vignettes and fewer vignettes to allow for more discussion time and inclusion of a discussion about implication of these clinical situations to research.

## 6. Outcomes

The second OZPOS and PoCoG Psycho-oncology Professional Day was once again successful in providing a dedicated forum for the excellent psycho-oncology research being conducted in Australia and creating an opportunity for researchers and clinicians to interact and exchange ideas. This year's meeting focussed on aspects of survivorship care and complex clinical cases in psycho-oncology. Once again the event successfully engaged junior researchers by giving them an opportunity to present and receive feedback about their work and establish more formal links with clinicians and researchers. The event also gave them the opportunity of being involved in the planning of the scientific program and taking on roles of session chairs.

The survey results indicate that the Professional Day was well received and provided useful feedback which will inform future planning of these meetings.

## 7. Acknowledgements

PoCoG and OZPOS would like to thank COSA for their generosity in contributing to the funding of the Professional Day and ASN events for their assistance with the venue arrangements. PoCoG and OZPOS would like to thank all of the Professional Day speakers and session chairs for their support in preparing the presentations and workshops, the COSA conference organisers for their assistance with general preparation and registrations for the day, and finally, all of the psycho-oncology professionals who attended and all of those participants who completed the evaluation survey.



## 8. Further enquiries

Further inquiries about the workshop report should be directed to:

PoCoG Executive Office

Tel: 02 9036 5002; Fax: 02 9036 5292; Email: [pocog.office@sydney.edu.au](mailto:pocog.office@sydney.edu.au)

## 9. Appendix

### **OZPOS and PoCoG Psycho-oncology Professional Day Detailed Program**



Clinical  
Oncological  
Society of  
Australia



# Optimising psychosocial care through clinical and research excellence

**OZPOS and PoCoG  
Psycho-oncology Professional Day**

**8 November 2010  
Melbourne Convention & Exhibition Centre**



# WELCOME

Welcome to the second OZPOS and PoCoG Psycho-oncology Professional Day 2010: *Optimising psychosocial care through clinical and research excellence*. This year's program focuses on aspects of survivorship and complex clinical cases in psycho-oncology. We hope you will find the discussions and presentations to be stimulating and educational.



**A/Prof. Jane Turner**  
Chair, The Australian Psychosocial Oncology Society Inc.  
(OZPOS)  
*Meeting convenor*



**Prof. Phyllis Butow**  
Chair, Psycho-oncology Co-operative Research Group  
(PoCoG)  
*Meeting convenor*



## PROGRAM OUTLINE

9.00 - 10.00	Plenary Session <b>CANCER SURVIVORSHIP: KEY ISSUES IN RESEARCH AND CLINICAL CARE</b>		
	Room 203		
10.00-10.30	Morning tea		
10.30-12.00	Research session 1 <b>WHAT ABOUT ME? CALD AND OTHER VULNERABLE GROUPS</b>	Research session 2 <b>WHAT'S HOT EMERGING RESEARCH IN PSYCHO-ONCOLOGY</b>	Clinical workshop <b>MINDFULNESS SESSION 1: MINDFULNESS IN ONCOLOGY</b>
	Room 203	Room 107	Room 108
12.00-13.00	Lunch / PoCoG AGM		
13.00-14.30	Panel discussion <b>CHALLENGES AT THE COALFACE: RESPONDING TO COMPLEX CLINICAL PROBLEMS</b>		
	Room 203		
14.30-14.45	Afternoon tea		
14.45-16.45	Research session 3 <b>PSYCHO-ONCOLOGY IMPLEMENTATION</b>		
	Room 107		
14.45-17.30	Clinical workshop <b>MINDFULNESS SESSION 2: CLINICAL PRACTICUM</b>	Clinical workshop <b>HELPING PARENTS WITH CANCER TO TALK WITH THEIR CHILDREN</b>	<b>POCOG OPEN SAC MEETING</b>
	Room 108	Room 204	Room 203

## PROGRAM IN DETAIL

**9.00 – 10.00** **Plenary session**  
**CANCER SURVIVORSHIP: KEY ISSUES IN RESEARCH AND CLINICAL CARE**  
 Chair: Phyllis Butow

Room 203 **9.00am** **Welcome**

**9.05am** **Afaf Girgis**  
 Cancer survivorship: issues for caregivers and families

**9.20am** **Janette Vardy**  
 Cognitive function in cancer survivors

**9.35am** **Michael Jefford**  
 Systematic approaches to cancer survivorship

**9.50am** **Discussion and close**

**10.00 – 10.30** Morning tea

**10.30 – 12.00**

Room 203 **Research session 1**  
**VULNERABLE GROUPS AFFECTED BY CANCER**  
 Chair: Laura Kirsten  
 Discussant: Matt Loscalzo

**10.30am** **Welcome**

**10.35am** **Gail Garvey**  
 Supportive Care Needs Survey for Australian Indigenous Cancer Patients (SCNS-IP)

**10.50am** **Tara Stern**  
 After cancer treatment: Assessing psychosocial needs and improving post-treatment care

**11.05am** **Kelvin Koay**  
 Prevalence of poor health literacy and associations with distress and other factors in patients with head and neck or lung cancer

**11.20am** **Phyllis Butow**  
 Can we talk to immigrants? An analysis of audio-taped oncology consultations

**11.35am** **Claire Wakefield**  
 “Suddenly he’s dropped from an A student to a C”: A qualitative investigation of the educational experiences and concerns of young cancer survivors and their families

**11.50am** **Discussion and close**



Room107 **Research session 2**  
**WHAT'S HOT - EMERGING RESEARCH IN PSYCHO-ONCOLOGY**  
 Chair: Nadine Kasparian

- 10.30am Welcome**
- 10.35am Sylvie Lambert**  
 Unmet supportive care needs among a population-based sample of partners and caregivers (P/Cs) of cancer survivors 6, 12, and 24 months post-diagnosis
- 10.50am Ben Smith**  
 Understanding the psychosocial sequelae of surviving testicular cancer
- 11.05am Rebecca Bergin**  
 The development of a nurse-led psychosocial intervention with peer support for women undergoing radiotherapy for gynaecological cancer
- 11.20am Vanessa Beesley**  
 Pancreatic cancer patients' supportive care needs and corresponding use of allied health services
- 11.35am Jane Hayman**  
 Preferred participation in treatment decision making over time among male cancer patients
- 11.50am Discussion and close**

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Room 108 **Clinical workshop**  
**MINDFULNESS SESSION 1: MINDFULNESS IN ONCOLOGY**  
 Facilitator: Elizabeth Foley  
 (pre-registration necessary)

**12.00 – 13.00** Lunch  
 PoCoG Annual General Meeting will be held for 15-20 min in room 203 immediately next to the lunch area. All are welcome to attend.

**13.00-14.30**

Room 203 **Panel discussion**  
**CHALLENGES AT THE COALFACE – RESPONDING TO COMPLEX CLINICAL PROBLEMS**  
 Chair: Matt Loscalzo  
 Panel members: Jane Fletcher, Brian Kelly, Carrie Lethborg

**14.30-14.45** Afternoon tea

**14.45-16.45**

Room 107 **Research session 3**  
**PSYCHO-ONCOLOGY IMPLEMENTATION**  
 Chair: Jaklin Elliott

- 2.45pm** **Welcome**
- 2.50pm** **Ben Britton**  
 Heads Up: A Phase II trial of a psychological intervention to reduce malnutrition and depression in head and neck cancer patients undergoing radiotherapy
- 3.10pm** **Kerrie Clover**  
 Comparison of desire for help with pain and desire for help with distress among oncology outpatients
- 3.30pm** **Jane Ussher and Janette Perz**  
 Gender differences in cancer carer psychological distress: An analysis of moderators and mediators
- 3.50pm** **Carrie Lethborg**  
 Answering the unanswered questions about psychosocial screening in the cancer setting
- 4.10pm** **Mirella Matthews**  
 Implementing routine supportive care across North Eastern Metropolitan Integrated Cancer Services: A network approach
- 4.30pm** **Discussion and close**

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**14.45-17.30**

Room 108 **Clinical workshop**  
**MINDFULNESS SESSION 2: CLINICAL PRACTICUM**  
 Facilitator: Elizabeth Foley  
 (pre-registration necessary)

Room 204 **Clinical workshop**  
**HELPING PARENTS WITH CANCER TO TALK WITH THEIR CHILDREN**  
 Facilitator: Jane Turner  
 (pre-registration necessary)

Room 203 **POCOG OPEN SAC MEETING**  
 (PoCoG members and meeting presenters only)  
 Chair: Janette Vardy

## CASE VIGNETTES FOR PANEL DISCUSSION

### Vignette 1

A young woman in her 20s has been diagnosed with cancer (a huge shock to her) and has undergone radiotherapy, with the prospect of major surgery after this. She is an only child, born and raised overseas, and has been in Australia for only a few years, with no other family here. Her father died from cancer last year, and she is still grieving for him. She is engaged and had planned to get married this year, but radiotherapy put her wedding plans on hold. Her illness has raised significant relationship problems with her fiancé and his parents around issues of loss of fertility, and the marriage has been postponed. She is no longer able to work due to her illness, and is very worried about not being able to keep up mortgage repayments on the unit she had recently bought, and hence losing her home. Her mother, who speaks no English, recently arrived from overseas to live with her and provide support, but soon after arrival began to experience the same symptoms that led to her daughter's cancer diagnosis, and herself requires medical investigations, which her daughter has had to try to organise around her own surgery and need for hospitalisation. After leaving her home country, her mother's home there was bulldozed in a government initiative of which she did not receive notification as she was already in Australia. There are significant tensions between the patient's partner and mother, who are now both living with the patient, and uncertainty as to whether the patient's relationship with her fiancé will continue, and when and where her mother will return home.

### Vignette 2

A 47-year-old woman recently diagnosed with an aggressive ER/PR negative grade 2 node positive breast cancer is referred to the psycho-oncology team for management of her anxiety and other psychosocial issues. She is a single mother of 2 boys aged 12 years and 9 years, living in Department of Housing accommodation. She is on a parent benefit from Centrelink, but has never been in paid employment. She has completed surgical treatment and is due for adjuvant chemo/radiotherapy. Her main presenting issue is needle phobia. She has been on the methadone program for 20 years and prior to this was an IV heroin user. She has admitted to the medical oncologist that she has been obtaining black market clonazepam and is scared that sharing that information with other team members will jeopardise her methadone program.

She currently is a heavy marijuana user smoking "30 cones per day". The patient refuses any port-a-cath / Hickmans or PICC line insertions and identifies 2 insertion points at which she will be 'okay' with cannulation (the wrist and the crook of her arm). She spends most of her day at home and has no social support network, no contact with the children's school and minimal contact with her family of origin. The school has expressed concerns in the past and suggested she walk the children to school, which she won't do. She reveals during assessment that her younger child has behavioural problems and has said that he would like to kill himself. Shortly after her first chemotherapy she refuses to see the medical oncologist again after the medical oncologist did not provide her with extra analgesics for a toothache, referring her back to her methadone prescriber for pain management. The medical oncologist cannot continue to prescribe chemotherapy without reviewing the patient but he is concerned that if the patient is not treated adequately now she will recur quickly.

### Vignette 3

A 64-year-old woman sought referral to the psycho-oncology team for assistance with "coping" following her husband's diagnosis with advanced pancreatic cancer. She has taken leave from her work to spend time with her husband before he dies. He has his own business but is no longer working full-time but will still do odd jobs – she calls him a "workaholic". She reports that their relationship has always been volatile and is more so now because they are spending all day together with her husband swearing and abusing her verbally when he is frustrated because he is unable to do things that he could do before. There is long standing strain in the marital relationship but in the past when they had an argument they both went to their respective jobs and 'all was forgotten' by the end of his long working day. Since his diagnosis, her husband refuses to allow their grandchildren to visit as they are 'too rowdy' – this is upsetting for her and her daughter. He does not like it when she is away from home for too long and will call her mobile to ask where she is in an aggrieved manner. She believes he is depressed and would like someone to give him some antidepressants however he does not discuss his emotions in consultations and when they are raised by the palliative care physician he minimises how bad he feels. She is also concerned because they have not engaged in sexual activity for a long time. She suspects this is due to a rash on her husband's

penis, which he has not revealed to any of his doctors. She approached the palliative care coordinator last week to see if she could “put him on some anxiety medication without him realising it - tell him it is medication for something else.”

She has never seen a mental health professional before. In the past she’s coped by keeping herself busy with work and by spending time with her children and grandchildren. She now feels that she is at ‘breaking point’ and reported poor mood but does not meet criteria for depression.

## Vignette 4

A 23-year-old woman working as a clerk is an in-patient in the oncology ward and the treating team have asked you to see her for “support”.

She is being treated for an aggressive upper GI cancer, unresectable, with significant local spread. She has had radiotherapy and is now having chemotherapy, and is in hospital because of complications from this. There was a delay in diagnosis as her GP did not suspect cancer, her symptoms were non-specific and her weight loss was deliberate, in preparation for her wedding six months ago.

She was born in Australia, of Lebanese Christian parents and her husband is Palestinian. They have no children, live in rented accommodation and don’t have much money as he’s just finishing his apprenticeship as a chef (working split shifts and odd hours). For both of them, their families of origin have significant problems, with conflict, family separations and long standing disputes. Her parents separated with great conflict when she was 13 and she largely ‘mothered’ her two younger brothers, moving into her own flat with them when she was 18. When her parents visit on the ward there is often hostility between them and on one occasion a physical confrontation.

The ward staff remark often how tragic this case is and how upset they feel when they go into the room. Some staff members have stayed back long after their shift finishes to provide “extra” care. They often exchange hugs with the patient and her husband. The patient has considerable insight. She reports symptoms of anxiety, especially about the family and her husband and how they will manage when she dies. In particular she is worried her husband will commit suicide.

## Vignette 5

Mr AB, age 59, is referred as an outpatient by one of the local haematologists. He is now 12 months post bone marrow transplant for CML, and has done very well medically. At his appointment two weeks ago the haematologist told him he was well enough to return to his job in the financial industry (he was

re-trenched just before his BMT and has been on income protection insurance payments). The haematologist was surprised by his lack of response to this news and has referred him as possibly depressed. He is not on any steroids.

Mr AB attends with his wife, but she stays in the waiting room. He is tall, thin and poorly groomed, with hair sticking up in all directions and food stains on his shirt. He was quite physically agitated in the waiting room, pacing up and down before the appointment.

He agrees he’s pretty low, but says it is all an understandable reaction to his situation. He does not think he’ll get another job and is sure they won’t be able to manage financially. He’s lying awake at night thinking about this and has been so concerned about the state of his finances he’s refused to let the family turn on the heaters over winter (it is now August). However, they own their own home and have so much in savings he and his wife can’t get Centrelink payments; their son (age 25) who lives at home has a good job in a bank and his daughter (age 23) is living independently about 50 kms away and is working as a lawyer in a big firm. He also has superannuation which he has not touched yet. His wife has not worked for years and didn’t need to.

As well as poor sleep with initial insomnia and classic early morning waking, his appetite is poor, food tastes “like cardboard”, he is anhedonic (but says this is because the only things he enjoyed in the past were physically active pursuits like running and hiking), has low motivation and complains of fatigue and deconditioning.

He does have thoughts about killing himself, perhaps by hanging, but denies any specific plans, though he is a bit evasive about this.

There’s no past history of psychological disorder or significant drug or alcohol use. He’s been married for 30 years and had a very stable work record before retrenchment. He was born in Scotland and is an only child. There was a lot of adversity in his early upbringing as his mother married 4 times, and the household was always impoverished. His mother died in Scotland around the time he had his BMT and he could not travel to attend the funeral. He feels very guilty about this and is ruminating about it and the circumstances of his mother’s death. His wife joins you and confirms the above history, but when self-harm is discussed she bursts into tears and says that two days ago she heard him moving around the house at 3am. When she got out of bed and offered to help him he said he was looking for the car keys – to gas himself with carbon monoxide. At this point Mr AB says he’s been researching successful suicide methods on the internet.

## WORKSHOPS

Please note that pre-registration for these workshops prior to the OZPOS and PoCoG Psycho-oncology Professional Day is required

### Mindfulness in Oncology

*FACILITATOR: DR ELIZABETH FOLEY*

The current research status of mindfulness in oncology will be discussed as well as the practical details for evaluating your practice (e.g. which mindfulness measure to use? etc). The workshop will focus on understanding how mindfulness works clinically and on polishing the various ways of introducing mindfulness to others.

### Mindfulness—Clinical Practicum

*FACILITATOR: DR ELIZABETH FOLEY*

This advanced session will be offered to clinicians who have experience using mindfulness within individual and group contexts. Improving clinician confidence in delivering flexible mindfulness training will be the focus of this workshop. The modification of mindfulness practices for cancer streams/stages/individuals will be addressed and the challenges of teaching mindfulness in this context will be discussed.

### Helping Parents with Cancer to Talk with their Children

*FACILITATOR: ASSOCIATE PROFESSOR JANE TURNER*

This advanced session will be offered to clinicians who have experience in providing support and counselling for patients with cancer, including those facing advanced disease.

The focus of the workshop will be to improve the knowledge of participants about the responses of children to parental cancer, and enhance confidence and skills in promoting enhanced parental communication with children. This will be achieved through provision of brief theoretical overviews before working through a series of role-plays designed to highlight common clinical problems, including parental avoidance, hostility, and family dysfunction. The workshop will draw on evidence from the literature on resilience and childhood bereavement to introduce approaches to optimise adjustment of children.

### About the facilitators

**Elizabeth Foley (BA Hons, MPsych, PhD)** is an internationally recognized clinician and researcher in the area of mindfulness. Beth has completed a PhD on the clinical application of mindfulness and has extensive training in MBCT & MBSR. Beth has completed several large-scale clinical trials of Mindfulness Based Cognitive Therapy for individuals diagnosed with cancer and is a published author in this area. Beth currently provides mindfulness based therapy to individuals and groups in private practice and in collaboration with the NSW and QLD Cancer Councils.

**Jane Turner (MBBS, PhD, FRANZCP)** is a consultation-liaison psychiatrist with 20 years' clinical experience in oncology. She has interests in the promotion of wellness after treatment for cancer, and the impact of advanced cancer on families, in particular the needs of children with a parent with cancer. She has extensive experience as an educator and has facilitated communication skills workshops nationally with clinicians from diverse professional backgrounds. Her PhD focused on the development and evaluation of an educational intervention to enhance the capacity of oncology nurses to provide information and support for parents with advanced cancer regarding the needs of their children. She was an expert advisor to the Cancer Council NSW for the development and subsequent revision of their resource: *When a parent has cancer: how to talk to your kids*.

## ABSTRACTS

### Plenary Session Cancer survivorship: Key issues in research and clinical care

#### *CANCER SURVIVORSHIP: ISSUES FOR CAREGIVERS AND FAMILIES*

A. Girgis, S. Lambert,  
T. W. Regan

Increasingly, researchers and clinicians are recognising the reverberating impact of a cancer diagnosis on patients' families. Upon diagnosis, families often find themselves grappling with intense emotions and existential concerns at the same time as they are providing support to patients, taking on novel care giving roles and responsibilities and attempting to remain afloat with other competing life events. In the midst of this whirlwind, patients and their caregivers may be struggling to find optimal coping strategies and adjust to potential disruptions in routines and activities. Despite efforts to manage care giving demands, these may inadvertently exceed caregivers' capabilities and result in them feeling burdened and exhausted. This presentation will provide an overview of the impact of a cancer diagnosis on families/ caregivers and interventions designed to assist them with the demands of their roles, with a particular focus on the survivorship stage.

#### *SYSTEMATIC APPROACHES TO CANCER SURVIVORSHIP*

M. Jefford

Around 3.2% of the Australian population, more than 700 000 people, have a personal history of cancer. Survivors may encounter a range of sequelae as a result of cancer and its treatments, including physical, emotional, psychological, practical and existential concerns.

Despite these complex issues, survivorship care is suboptimal, inconsistent and fragmented, with many survivors reporting unmet needs.

Survivors require ongoing follow-up care that focuses on (1) prevention and detection of new cancers and recurrent cancer, (2) surveillance for cancer spread, recurrence or second cancers, (3) interventions to deal with the broad consequences of cancer

and its treatment and (4) coordination between specialists and primary care providers. Survivorship care should be patient-centred, flexible, tailored to individual needs, cost-efficient, equitable and sustainable.

There are significant barriers to ideal care, including a focus on cancer as an acute illness and an emphasis on the diagnostic and treatment phase, limited health professionals' awareness of survivorship issues, lack of clarity regarding responsibility for survivorship care, and a paucity of established, effective models of care.

Further development of evidence-based follow up guidelines, screening and assessment tools, survivorship care plans, piloting of various models of post-treatment care, and education and training programs are crucial to improving survivorship outcomes.

Other key areas for research include more comprehensive evaluation of the long-term effects of cancer and treatments (for survivors, carers and families, including minority and disadvantaged populations), evaluation of lifestyle factors and self-care behaviours on survivorship outcomes, refinement of measurement tools, and the development of measures of quality survivorship care.

#### *COGNITIVE FUNCTION IN CANCER SURVIVORS*

J. Vardy, H. Dhillon

A large percentage of cancer survivors report that their memory and concentration is impaired after receiving cancer treatment. For most patients any cognitive impairment is subtle and improves after ceasing chemotherapy, but for a subset of patients the symptoms are sustained and can impact on their quality of life and ability to function.

Earlier studies, mainly cross sectional in design, reported that 15 - 50% of adults with solid tumors not involving the central nervous system (CNS) have cognitive impairment after chemotherapy, but recent studies suggest that about 20-30% have cognitive problems. Prospective studies also report that up to 30% of patients with breast and colorectal cancer have cognitive impairment prior to receiving chemotherapy. Most studies report a decline in cognition in a subset of patients after chemotherapy, although some studies have reported no significant change.

There is only a weak association between self-reported cognitive function and neuropsychological performance on formal cognitive testing. Self-reported cognitive impairment is strongly associated with fatigue, symptoms of anxiety and depression and impaired quality of life; however none of these symptoms are correlated with neuropsychological impairment on cognitive testing. The underlying mechanisms of cognitive impairment in cancer survivors are unknown, and there is no proven intervention to prevent it from occurring or to treat it once it has occurred.

### Session 1 Vulnerable groups affected by cancer

#### *SUPPORTIVE CARE NEEDS SURVEY FOR AUSTRALIAN INDIGENOUS CANCER PATIENTS (SCNS-IP)*

G. Garvey, V. L. Beesley C. Jacka,  
M. Janda, L. Whop, P. O'Rourke,  
A. Green, P. C. Valery

**Aims:** There are several validated measures to assess supportive care needs (SCN) in cancer populations, and a variety of supplementary modules for group-specific needs however, these have not been validated for Indigenous Australians who generally have higher death rates from cancer compared to other Australians. We aimed to assess the face and content validity of an existing 34 item SCN survey tool (SCNS-SF34) for Indigenous cancer patients and to develop a culturally appropriate subscale.

**Methods:** 30 face-to-face interviews with Indigenous cancer patients and 5 focus groups with health professionals/key-informant community members were conducted. These were guided by semi-structured questions about the cultural acceptability and utility of the tool for Indigenous cancer patients.

**Results:** Participants agreed that the original survey required substantial changes. All original items were shortened/changed/re-worded to use Indigenous friendly language (e.g. depressed was substituted with sad). Seven items were omitted (e.g. item on death and dying) as they were culturally inappropriate and 12 new items added (e.g. 'Having traditional bush tucker in hospital'). Sexual items were made optional

as these were considered culturally inappropriate by some but important to others. Participants also stated the overarching question and response options were confusing so these were amended.

**Conclusion:** This study resulted in the development of a culturally appropriate and acceptable needs assessment tool for use with Indigenous cancer patients. It will enable a more comprehensive approach to assessing the supportive care needs of this group. Further work to determine the appropriate response to unmet needs for improving cancer outcomes in this group is warranted.

#### **AFTER CANCER TREATMENT: ASSESSING PSYCHOSOCIAL NEEDS AND IMPROVING POST-TREATMENT CARE**

T. Stern, K. Baxter, F. Hammond, A. Reid, S. Tuffin

In Australia, post-treatment psychosocial programs and research have been minimal, and the unmet needs of cancer survivors require increased attention and intervention (Hodgkinson et al, 2007).

A multi-disciplinary, quality-improvement project was established, focusing on the transition period from active treatment to non-palliative post-treatment care. The overall aims of the project were: a) to reduce the burden of survivorship and b) to provide cost-effective and appropriate comprehensive survivorship care.

The first phase of the project evaluated existing psychosocial support provided upon treatment completion. A questionnaire developed for this project identified unmet needs and patient satisfaction levels. As informed from Phase 1 data, Phase 2 involved implementing and evaluating changes to post-treatment care. The interventions at Phase 2 were: a) an "After Treatment Screening Tool", and b) provision of an "After Treatment Information Pack".

Anonymous patient surveys were collected within one month of finishing curative treatment (n=48 and n=47 in Phase 1 and 2 respectively). Overall quality of life significantly improved from Phase 1 to Phase 2 (FACT-G; Webster et al, 2003). There was a substantial improvement across phases in reported patient concerns associated with information needs, medical communication, and managing side-effects. Informational needs

decreased dramatically post-intervention and psychosocial referrals reduced from 25% to 15%.

This project demonstrated that effective, inexpensive changes to service delivery targeted unmet post-treatment needs. Recommendations for post-treatment psychosocial care, as informed by this multi-disciplinary project, will be discussed.

#### **PREVALENCE OF POOR HEALTH LITERACY (HL) AND ASSOCIATIONS WITH DISTRESS AND OTHER FACTORS IN PATIENTS (PTS) WITH HEAD AND NECK (H+N) OR LUNG CANCER**

K. Koay, P. Schofield, K. Gough, R. Buchbinder, D. Rischin, J. Corry, D. Ball, M. Jefford

**Aims:** HL refers to the capacity to seek, understand and utilise health information to make informed health decisions. Pts with low HL experience worse outcomes. This study assessed: (1) level of HL in pts treated for H+N or lung cancer, (2) associations between HL and demographic factors and distress levels, (3) further validation of the Health Literacy Management Scale (HeLMS).

**Methods:** Consecutive English-speaking pts were approached within one month of diagnosis. Planned accrual was 80 pts. HL was assessed using the Shortened-Test of Functional Health Literacy in Adults (S-TOFHLA) and HeLMS. HeLMS measures eight domains of HL, while S-TOFHLA focuses on 'understanding health information'. Distress assessed by Distress Thermometer (DT, 0-10). Data collection via 1:1 interview.

**Results:** Response rate was 72.7% (128 approached, 101 consented, 93 completed). Mean age was 61.8 (range 27-92); 82.8% male. According to S-TOFHLA 5.4% of pts had inadequate HL, 6.5% marginal and 88.1% adequate HL. 69.9% pts could not interpret prescription labels, 30.1% could not understand a standard appointment card. 17.2% of pts had some problems with HL according to HeLMS. Poor HL (S-TOFHLA) was associated with old age and low education level (p=0.043 & p=0.009). Low scores on various domains of HeLMS were associated with lower education level and young age. S-TOFHLA scores significantly correlated with 'understanding health information' domain on HeLMS (p=0.014). 50.5% of pts had high levels of distress (DT ≥4), but no relationship was found between

S-TOFHLA scores and distress.

**Conclusions:** A substantial proportion of pts appear unable to understand common written medical instructions. HeLMS may represent a more comprehensive HL instrument. Strategies to identify and better support pts with HL difficulties need to be developed.

#### **CAN WE TALK TO IMMIGRANTS? AN ANALYSIS OF AUDIOTAPED ONCOLOGY CONSULTATIONS**

P. Butow, M. Sze, L. Aldridge, M. Bell, M. Eisenbruch, R. Iedema, S. Dong, S. Abdo, I. Wan, M. Mikhail, R. Hui, J. Vardy, R. Asghari, D. Goldstein

Immigrants with cancer report challenges communicating with their health team. This study aimed to explore differences in communication patterns between medical oncologists and immigrant versus Anglo-Australian patients.

**Patients and Methods:** Consecutive cancer patients who had newly diagnosed incurable cancer who had either immigrated to Australia from countries where Arabic, Cantonese, Mandarin or Greek is spoken or were of Anglo-Australian ethnicity, and where possible at least one family member, were recruited from the practices of 10 medical oncologists in nine hospitals. The first two consultations after diagnosis of metastatic disease were audio-taped, transcribed, translated into English and coded.

**Results:** 47 immigrant and 31 Anglo Australian patients and 74 immigrant and 38 Anglo-Australian family members participated, yielding 141 audio-taped consultations. Consultation length did not differ significantly between groups but was longest for Anglo-Australians (3345 words), versus for immigrants with interpreters, excluding translation, (2961 words). Doctors spoke more to Anglo-Australians than to immigrants with interpreters (2246 vs. 1627 words, p = 0.002), and immigrant patients with interpreters spoke less to doctors than Anglo-Australians (319 vs 727 words, p < 0.0001) and immigrants without interpreters (427 fewer words, p = 0.0001). Doctors spent proportionally less time with immigrants with interpreters speaking about cancer related issues (p = 0.002), summarising and informing (p ≤ 0.0006), and conversely, spent more time talking about other medical issues (p = 0.002), directly advising and asking questions (p = 0.002). Anglo-Australian patients

spoke more about psycho-social issues than did immigrants with interpreters ( $p < 0.0001$ ) but the latter gave more high intensity cues (11.1 versus 7.4). 26.5% of cues in consultations involving interpreters were not interpreted. Of interpreted cues, there was a trend towards more immigrant than Anglo-Australian cues not being responded to, delayed or ignored (12% vs 5%,  $p = 0.07$ ).

**Conclusions:** This is the first study to record and code consultations with immigrant cancer patients. Doctors say less to immigrant patients, and respond to fewer cues. Guidelines are needed for communication with immigrant patients.

*“SUDDENLY HE’S DROPPED FROM AN A STUDENT TO A C”: A QUALITATIVE INVESTIGATION OF THE EDUCATIONAL EXPERIENCES AND CONCERNS OF YOUNG CANCER SURVIVORS AND THEIR FAMILIES.*

C. E. Wakefield, J. K. McLoone, C. Fleming, P. Butow, R. J. Cohn

Re-engaging in education after cancer is an important, yet difficult, transition for young survivors due to extensive absenteeism, ongoing health concerns and social challenges.

**Aims:** 1) To investigate young survivors’ and their siblings’ perceived changes in academic performance, use of educational support and future education/career plans. 2) To explore any changes in parental achievement expectations and involvement/advocacy in their childrens’ education post-cancer.

**Methods:** All families of Sydney Children’s Hospital patients (>12 years) who finished treatment in 2008/09 were invited to participate in a semi-structured telephone interview. The 70 participants included 19 survivors (mean age:16.1), 21 mothers, 15 fathers and 15 siblings (response rate=36%). Data were analysed using Miles and Huberman (1994) methodology and NVivo8. Emergent themes were cross-tabulated and counts were used to moderate researcher bias.

**Results:** Almost all survivors planned to, or had completed high school ( $n=18$ ), and 17 planned to attend university/college. Approximately half perceived a decline in academic performance (especially mathematics/science), however few reported concern about this and several felt more motivated

to achieve academically. More survivors than siblings received academic support (e.g. additional exam-time) and all survivors utilised supplementary tutoring. Fellow students and teachers appeared compassionate; however, survivors receiving private education appeared better supported. All survivors had clear career aspirations, many in the ‘helping’ professions (e.g. psychology/radiology/teaching/ministry). Parents were more troubled about academic declines and potential limitations on career opportunities, although many prioritised minimising stress on their recovering child. Siblings felt their education had been interrupted by their brother/sister’s cancer and appreciated additional parental involvement post treatment. The most challenging education-related events were changing schools, progressing to a new grade and commencing university/college.

**Conclusions:** Young cancer survivors and their siblings are eager to continue their education post-cancer. Families appreciate the educational assistance already received, however continued support beyond cancer is warranted, particularly at key educational transitions.

## Session 2 What’s hot – Emerging research in psycho-oncology.

### *UNMET SUPPORTIVE CARE NEEDS AMONG A POPULATION-BASED SAMPLE OF PARTNERS AND CAREGIVERS (P/Cs) OF CANCER SURVIVORS 6, 12, AND 24 MONTHS POST-DIAGNOSIS*

A. Girgis, S. Lambert, P. McElduff

**Aims:** Report on the level and type of unmet needs as well as the predictors of moderate/high unmet need count among P/Cs of cancer survivors.

**Methods:** P/Cs were identified through a population-based sample of cancer survivors participating in CHERP’s Cancer Survival Study. Participants completed a self-report survey at approximately 6 ( $n=547$ ), 12 ( $n=521$ ) and 24 ( $n=442$ ) months post-diagnosis of the survivor. Unmet needs were captured by the Supportive Care Needs Survey – P/Cs. Descriptive statistics were performed to identify level and

type of unmet needs and negative binomial regression to determine the predictors of the moderate/high need count. Predictors examined included caregiving roles, physical health, psychological morbidity, coping strategies, and social support.

**Results:** At 6, 12, and 24 months, 50%, 36%, and 30% of P/Cs reported at least one moderate/high unmet need, respectively. On average, P/Cs reported 4.63 ( $sd = 8.00$ ), 2.89 ( $sd = 6.38$ ) and 2.05 ( $sd = 5.40$ ) moderate/high needs at 6, 12, and 24 months, respectively. Many of the top ranking needs remained the same at 6, 12, and 24 months and included ‘managing concerns about cancer coming back’, ‘reducing stress in the person with cancer’s life’, and ‘understanding the experience of the person with cancer’. However, at 12 and 24 months, needs such as ‘accessing information about treatment’ became less prevalent and were replaced by more P/C-focused needs, such as ‘looking after your own health’. The significant predictors of moderate/high unmet need count will be presented and discussed.

**Conclusion:** Half of the P/Cs experienced at least one moderate/high unmet need at 6 months post-diagnosis, with almost one-third still experiencing moderate/high needs 2 years post-diagnosis of the survivor. Understanding the unmet needs experienced by P/Cs and identifying those at increase risk of reporting unmet needs is critical for evidence-based health care planning and resource allocation.

### *UNDERSTANDING THE PSYCHOSOCIAL SEQUELAE OF SURVIVING TESTICULAR CANCER*

B. Smith, M. King, P. Butow, I. Olver, T. Luckett, P. Grimison, G. Toner, M. Stockler, E. Hovey, J. Stubbs

Testicular cancer (TC) is the most common form of cancer (excluding skin) in Australian men aged 15-35 years and its incidence is rising. Although more than 95% of men with TC are cured, ongoing physical and psychological effects related to the diagnosis and treatment of TC may negatively affect their long-term psychosocial wellbeing. However, few studies have examined long-term psychosocial outcomes in TC survivors (TCSs).

**Aims:** To explore the experiences of TCSs.

**Methods:** This study is part of a large cross-sectional survey being conducted by PoCoG and ANZUP



investigating the prevalence and correlates of depression, anxiety, and psychosocial distress in Australian TCSs compared to the general population. An equal number of survivors recruited from hospitals around Australia who reported either: a) normal or b) severe/extremely severe levels of depression or anxiety on the Depression Anxiety Stress Scale were invited to take part in a qualitative interview. These semi-structured telephone interviews explored difficulties faced by TCSs and views on factors that contributed to or alleviated those difficulties. Interviews were audio-taped, transcribed, and coded for themes using an interpretive phenomenological approach.

**Results:** Thematic saturation was reached after 26 interviews. Difficulties experienced by TCSs related to four superordinate themes: loss of confidence in self and others, loss of normal identity, loss of capacity, and conflicting expectations. Most TCSs felt ill prepared to deal with a cancer diagnosis so early in their lives, which exacerbated difficulties. Re-establishing a new normal and social comparison and support alleviated difficulties.

**Conclusions:** The results of this study provide an in-depth understanding of the challenges faced by TCSs and factors that facilitated or impeded coping. These findings will complement results from the ongoing cross-sectional survey to inform the better design, focus, and timing of multi-disciplinary interventions to improve long-term psychosocial outcomes in this population.

#### *THE DEVELOPMENT OF A NURSE-LED PSYCHOSOCIAL INTERVENTION WITH PEER SUPPORT FOR WOMEN UNDERGOING RADIOTHERAPY FOR GYNAECOLOGICAL CANCER (GC)*

R. Bergin, S. Grogan, K. Sharkey, I. Juraskova, L. Mileskin, M. Krishnasamy, A. Hocking, D. Bernshaw, S. Aranda, P. Schofield

Radiotherapy for GC has numerous potentially distressing side effects which impact on psychosocial functioning and intimate relationships. Distress associated with diagnosis and treatment can be ameliorated by comprehensive treatment preparation and addressing informational, physical and psychosocial needs during treatment. The objective was to

develop, refine and pre-test an intervention package combining tailored nursing consultations with peer support (GC survivor).

Drawing on literature reviews and consumer input, a 3-stage process for developing complex interventions based on UK Medical Research Council (MRC) Framework, was used. This comprised: (1) Problem definition; (2) Refining the intervention; and (3) Pre-testing the intervention.

Two intervention manuals were drafted based on identified unmet needs and best available evidence for self-care. The nurse manual specified the content of consultations providing tailored information, self-care coaching and multi-disciplinary team care-coordination. The peer manual described the content of phone calls to provide psychosocial support and encourage adherence to the self-care plan. Intervention sessions were delivered at critical time-points in the illness trajectory: pre-, mid-, end- and post-treatment. The manuals were refined by iterative clinician and consumer review. Peers and nurses were rigorously trained and pre-testing with qualitative data collection completed. The study design and manuals were revised based on participant and clinician feedback.

The MRC Framework was appropriate to guide intervention development, resulting in two manuals as part of an intervention package. The package was well-received by consumers and multidisciplinary clinicians. An RCT will assess the effectiveness of this intervention to reduce psychological and symptom distress, psychosocial needs and psychosexual difficulties.

#### *PANCREATIC CANCER PATIENTS' SUPPORTIVE CARE NEEDS AND CORRESPONDING USE OF ALLIED HEALTH SERVICES*

V. Beesley, M. Janda, D. Wyld, H. Gooden, R. Neale

**Aim:** People diagnosed with pancreatic cancer have the worst survival prognosis of any cancer. No previous research has documented the supportive care needs of this population. We aim to describe, within an ongoing pancreatic cancer case-control study, the supportive care needs and support services accessed by the patients.

**Methods:** Seventy-two newly-diagnosed Queensland pancreatic cancer patients participated in a mail

survey (72% response rate). The questionnaire included a validated instrument to assess 34 need items across 5 domains (SCNS-SF34) and assessed the use of 21 community or allied health services. We analysed reported needs and corresponding services used.

**Results:** Participant's mean age was 63 years and 54% were male. On average, pancreatic cancer patients reported a median of 35 physical, 26 psychological, 25 information, 25 health care and 0 sexuality unmet needs (median standardised score, range 0-100). Overall, 86% of patients reported a need for help with at least one of the ten psychological need items. Of these 13% consulted a psychologist, psychiatrist, social worker or telephone counsellor, 75% reported having at least one of their psychological needs satisfied and 3% reported having all psychological needs satisfied. Furthermore, 70% of patients reported a need for help with pain. Of these 10% accessed a pain specialist and 36% had their need for help satisfied. The five most frequently reported moderate-to-high unmet need items pertained to the psychological and physical domains and included: 'needing help with uncertainty about the future' (34%), 'concerns about the worries of those close' (34%), 'not being able to do the things they used to do' (32%), 'pain' (30%) and 'fears about the cancer spreading' (30%).

**Conclusion:** Compared to other cancer populations, extremely high levels of unmet needs were reported by people with pancreatic cancer. Further work to improve the availability and uptake of appropriate supportive care is warranted.

#### *PREFERRED PARTICIPATION IN TREATMENT DECISION MAKING OVER TIME AMONG MALE CANCER PATIENTS*

J. Hayman, V. M. White, P. M. Livingston, S. Dunn, E. Maunsell, D. Hill

**Aim:** To examine whether role preferences in medical decision making change over time among male cancer patients.

**Methods:** A prospective, longitudinal study was conducted.<sup>1</sup> Eligible participants were males diagnosed with prostate or colorectal cancer. The Control Preferences Scale<sup>2</sup> was completed by participants at baseline, 4, 7, and 12 months post-diagnosis.

**Results:** 493 (86%) completed all four surveys. Participants were aged between 33 and 86 years of

age (M = 64.0 years, SD = 8.5). At baseline, 36% preferred an active role, 37% preferred a collaborative and 27% reported a passive role. Decision-making role preferences were most stable over time for those preferring an active role. Among those preferring an active role at baseline, the majority reported the same preference at 4-months (74%) and 7- and 12-months post-diagnosis (72% and 66% respectively). The majority of those who changed preferences in this group reported a preference for a collaborative role at the three follow-ups. Among those preferring a passive role at baseline, 63% reported the same preference at 4-months, 64% at 7-months and 58% at 12-months. Preference for a collaborative role was least stable over time. Of those who preferred this role at baseline, approx 50% reported a different preference at each follow-up, with approximately half moving to a passive role and half moving to an active role ( $\chi^2=93.01$ ;  $p<0.01$ ). At each time point, those who preferred an active role were significantly more likely to be  $\leq 64$  years and prostate cancer patients. Preference for a collaborative role was not significantly related to age or cancer type.

**Discussion:** Between one quarter and one half of male patients changed their preferred role in treatment decisions over the course of their treatment, compared to when first diagnosed. Clinicians need to regularly assess patients' desired level of involvement to ensure patients have the role they prefer in treatment decisions.

### Session 3: Psycho-oncology implementation

#### HEADS UP: A PHASE II TRIAL OF A PSYCHOLOGICAL INTERVENTION TO REDUCE MALNUTRITION AND DEPRESSION IN HEAD AND NECK CANCER PATIENTS UNDERGOING RADIOTHERAPY.

B. Britton, K. Clover, A. Baker, G. L. Carter

Mortality and morbidity from Head and Neck Cancer (HNC) are affected by nutritional outcomes. We previously established that a depression score was the best predictor of malnutrition during radiation therapy treatment.

**Aims:** To test the efficacy of a

psychological intervention in reducing malnutrition and depression in HNC patients undergoing radiotherapy.

**Methods:** This phase II clinical trial compared recent historical controls with a current cohort of HNC patients that received a psychological intervention. Eligibility criteria, recruitment procedures and outcome assessments of the two cohorts were identical. New HNC patients at Calvary Mater Newcastle (>20 fractionations) completed assessments in the first (T1) and last (T2) weeks of radiotherapy and 4 weeks post-treatment (T3). Assessments comprised: the Patient Generated Subjective Global Assessment (PGSGA) for nutrition; and the Patient Health Questionnaire-9 (PHQ-9), for depression. The intervention was: ultra-brief, introduced as part of the normal multidisciplinary care of HNC patients; conducted in the radiation oncology department; and scheduled immediately prior to or following other medical appointments. All participants received one session combining Motivational Interviewing (MI) and psycho-education prior to radiotherapy, and a second session two weeks later. Patients with depression also briefly saw the psychologist twice weekly throughout treatment.

**Results:** Seventy patients (94% consent) were recruited to the intervention study, with complete data on 63 patients. Participants were mostly male (95%) and ranged in age from 37 to 78. No significant demographic differences were found between intervention and controls. Linear Mixed Models analysis will be used to determine the overall difference between the intervention cohort and historical controls on nutrition, ECOG and depression measures at Time 2 and 3, adjusted for confounders (age, gender, RT fractions, cancer stage, PEG etc). Subgroup analysis was conducted for patients with depression.

**Conclusion:** Feasibility and acceptability were demonstrated through a high consent rate, intervention attrition and recorded participant comments.

#### COMPARISON OF DESIRE FOR HELP WITH PAIN AND DESIRE FOR HELP WITH DISTRESS AMONG ONCOLOGY OUTPATIENTS

K. Clover, G. L. Carter, P. Kelly, K. Rogers

Screening for pain and distress as the fifth and sixth vital signs

has been proposed as a way of increasing recognition and management of these symptoms. However, there is a consistent finding that not all patients accept available support services. Improved understanding of patients' desire for help may contribute to improved targeting and uptake of the effective treatments that are available.

Data were collected as part of the QUICATOUCH clinical screening program at Calvary Mater Newcastle, a major regional hospital in NSW Australia. Patients over threshold for pain (>0/10 on a pain thermometer) were asked if they would like help with their pain. Patients over threshold for distress (>3/10 on the Distress Thermometer) were asked if they would like help with their distress. Logistic regression analyses were conducted for (1) desire for help with pain and (2) desire for help with distress using the predictor variables age, gender, clinic type, treatment status, pain, distress and total score on the 'PSYCH-6', a scale measuring symptoms of anxiety and depression.

2266 patients undertook screening. 305 patients were over threshold for pain. At a pain score of one, 13% wanted help, increasing to 90% at a pain score of 10. Desire for help with distress among the 274 patients over threshold increased from 21% (at 4/10) to 41% (at 10/10). Pain intensity significantly predicted desire for help with pain (Odds Ratio (OR) = 1.50, 95% Confidence Interval (95%CI) = 1.33 to 1.70). PSYCH-6 score significantly predicted desire for help with distress (OR = 1.40, 95%CI = 1.26 to 1.56).

Desire for help with severe distress was lower than desire for help with severe pain. Patient reluctance to seek help for distress may constitute a barrier to realising the full potential of screening programs in improving symptom management.

#### GENDER DIFFERENCES IN CANCER CARER PSYCHOLOGICAL DISTRESS: AN ANALYSIS OF MODERATORS AND MEDIATORS

J. M. Ussher, J. Perz, P. Butow, G. Wain, C. Joyce, M. Sandoval

There is consistent research evidence that women cancer carers report higher rates of depression and anxiety than men, however there is little understanding of the mechanisms underlying these gender differences. The aim of this study was to examine the potential mediating roles of burden of care,

unmet needs, self-silencing, self-efficacy, and optimism, and the potential moderating influence of social support, cancer stage, patient gender, time spent caring and other responsibilities, on gender differences in Australian cancer carer distress. Four hundred and eighty four informal carers (329 women and 155 men), across a range of cancer types, stages and relationship dyads, completed a battery of questionnaires. Women cancer carers reported significantly more anxiety (HADS), burden of care (CRI: 'Health problems, 'Lack of family support'), and unmet emotional, spiritual and identity needs (PNI) than men. In the mediation analysis, gender differences in anxiety were fully explained by both the independent contribution and combination of: Disrupted Schedule, Health Problems (CRA), and Emotional and Spiritual Unmet Needs (PNI). Three continuous variables were assessed for their ability to moderate the relationship between gender and anxiety in separate multiple regression analyses. The interaction term was not significant for hours providing direct care, hours providing companionship and hours of received social support suggesting that these variables do not moderate the relationship between gender and anxiety distress. It is concluded that women's gendered role is associated with unmet needs and burden of care, resulting in greater anxiety in women cancer carers.

#### **ANSWERING THE UNANSWERED QUESTIONS ABOUT PSYCHOSOCIAL SCREENING IN THE CANCER SETTING.**

C. Lethborg, R. Brown

**Introduction:** While distress screening (DS) using validated measures in the cancer setting has successfully been trialled in relation to acceptability and validity, the issue of sustainability and clinical utility remains under explored.

**Aims:** To trial a distress risk factor screening (RFS) process as compared to the use of a validated distress screening tool (Distress Thermometer) in relation to utility, clinical activity, time required to screen and desire for help (Help Thermometer) in the cancer service of a general hospital.

**Results:** Of the 276 participants, a little more than half were found to be 'at risk' of distress using either method of screening. However, they were not necessarily the same people. Both screening methods

required prohibitive amounts of time per patient to be able to be implemented without significant clinical staff involvement.

Only a portion (30%) of the 'at risk' group indicated a desire for help and alerting clinical staff to risk of distress did not alter the amount of support they provided. In fact, a high percentage (92%) of participants was already receiving some form of supportive care, regardless of risk.

**Conclusion:** The implementation of DS in a busy cancer service is more complex and time consuming than is often suggested and is not possible without specific funding for administrative support and significant time from clinical staff. Any additional funding available may well be better spent on staff trained to provide assessments and interventions to support patients and carers in distress.

#### **IMPLEMENTING ROUTINE SUPPORTIVE CARE ACROSS NORTH EASTERN METROPOLITAN INTEGRATED CANCER SERVICES (NEMICS): A NETWORK APPROACH**

M. Matthews, K. Simons, C. Scott, P. Mitchell

**Introduction:** Challenges involved in translating best practice supportive care into clinical care are well documented. Following the publication of the Victoria's Cancer Action Plan 2009-2011 and the supportive care policy for Victoria, Integrated Cancer Services (ICS) including NEMICS, were tasked with facilitating the introduction of systematic supportive care into routine cancer care within their member health service. This paper outlines an analysis of the NEMICS approach to optimising equitable access to supportive care across the north east Melbourne.

**Methodology:** An analysis of the NEMICS Supportive Care Grant Program (SCGP) documentation and evaluation in light of Schofield et al (2006) discussion of barriers to the provision of evidence-based psychosocial care in oncology.

**Results:** All predisposing, enabling and reinforcing factors described as barriers to implementing routine supportive care were identified. A map of the barriers and the strategies used to overcome these will be presented.

**Discussion:** NEMICS worked collaboratively with its health services on establishing a model for supportive care screening,

building capacity within organisations and identifying referral pathways. Providing short term resources to health services to implement the supportive care policy with clear guidance from NEMICS was an enabling strategy. This network approach to change in practice enabled four health services to share information and problem solve collaboratively with NEMICS serving as an enabling hub.

**Conclusion:** ICSs are well positioned to facilitate the implementation of routine and systematic supportive care within their respective geographical regions.

## PRESENTERS

### Discussion panel members

#### **A/Prof. Matthew J. Loscalzo, L.C.S.W.**

*Liliane Elkins Professor in Supportive Care Programs  
Administrative Director, Sheri & Les Biller Patient and Family Resource Center  
Executive Director, Department of Supportive Care Medicine, City of Hope National Medical Centre  
Professor, Department of Population Sciences  
City of Hope*

Mr. Loscalzo focuses on the psychosocial aspects of cancer, and how patients and their families cope with cancer and its treatments at all points along the disease continuum. Areas of focus include: gaining a better understanding of how people manage distress and make adaptations that result in growth and positive change; teaching women and men how to get the best out of each other when they are under stress; implementing problem-based distress screening procedures that prospectively identify patients requiring assessment and possible intervention to remove barriers to medical care and to support optimal coping; testing problem-solving models that enable patients and family members to maximize the benefits of medical care; testing psycho-behavioural and other strengths-based interventions related to palliative care and coping; testing models that enhance gender communication relating to stressful events, especially chronic illness.

#### **Dr Jane Fletcher**

*Director/ Psychologist, Melbourne Psycho-oncology Service, Cabrini Health, Melbourne*

Jane has primarily worked as a psychologist/psycho-oncologist in private practice in Melbourne. In addition to her work in private practice, Jane is also Deputy Head of the Cabrini Monash Psycho-oncology Research Unit. She is the current chair of the Victorian Cooperative Oncology Group's Psycho-oncology Committee and is a member of the Palliative Care and Gynecological Cancer committees. In addition to her interests in palliative care and gynecological cancer, Jane has extensive experience dealing with issues such as anxiety, depression, and the grief and loss associated with a cancer diagnosis.

#### **Prof. Brian Kelly**

*Professor of Psychiatry, School of Medicine and Public Health, University of Newcastle*

Prof Kelly is a Psychiatrist and has been undertaking research and clinical practice in psycho-oncology, with a particular interest in palliative care, and has experience in developing services in rural and remote regions.

#### **Dr Carrie Lethborg**

*Clinical Leader, Cancer Social Work Coordinator Psycho-social Services St Vincent's Hospital, Melbourne*

Dr Carrie Lethborg has worked as a clinician and researcher in the cancer field for over 20 years and is currently completing her Post Doctoral Study trialling a meaning and purpose based intervention. She is the Deputy Chair of the Victorian Co-operative Oncology Group, Psycho-oncology Committee and the Victorian Chair of Oncology Social Work Australia.

### Research session chairs

#### **Prof. Phyllis Butow**

Professor Phyllis Butow has been Chair of PoCoG since its establishment in 2005 and is based at The University of Sydney. Phyllis is a world leader in psycho-oncology research with over 20 years experience in the area. In 2009, Phyllis received an International Psycho-Oncology Society award for her outstanding contribution to the field of psycho-oncology.

#### **Dr Jaklin A. Elliott**

*Social Scientist, Cancer Council Australia*  
Jaklin Elliott works as a Social Scientist for Cancer Council Australia, and is a Visiting Research Fellow and Affiliate Lecturer with The University of Adelaide where she lectures and supervises students. She is also the Convenor of the recently formed South Australian Interest Group of PoCoG. She uses qualitative methodologies to examine how people talk about their experiences and perceptions of cancer, and the implications of different ways of understanding for individuals, carers (personal and professional), and society in general. Her current research projects and interests include cancer and the media, complementary and alternative medicines use in people with cancer, hope, euthanasia,

cancer clusters, as well as the decision-making and communication issues for people affected by cancer, particularly considering the family.

#### **Dr Nadine Kasparian**

Nadine Kasparian is a Psychologist and NHMRC Postdoctoral Research Fellow in the Faculty of Medicine at the University of NSW. Over the past nine years, her work has focused on the development of strategies and interventions to meet the psychological and supportive care needs of individuals affected by hereditary cancer. She has worked closely with people affected by melanoma, non-melanoma skin cancer, breast and ovarian cancer, and rare conditions such as Von Hippel Lindau syndrome. Nadine is also Head of Psychological Research and Supportive Care at the Heart Centre for Children, The Children's Hospital at Westmead.

#### **Dr Laura Kirsten**

*Clinical Psychologist, Nepean Cancer Care Centre, Sydney West Cancer Network*

Laura Kirsten is a clinical psychologist who provides care to medical oncology, radiation oncology, haematology and palliative care patients and carers of the Nepean Cancer Care Centre. Laura is actively involved in research and has been a member of both OZPOS and PoCoG since their inception. Laura currently chairs the NSW Psychologists in Oncology group.

### Plenary presenters

#### **Prof. Afaf Girgis**

Afaf is the Director of the Centre for Health Research & Psycho-oncology (CHeRP) of the Cancer Council NSW, conjoint Professor in the Faculty of Health at the University of Newcastle & Chair of the Hunter Medical Research Institute's Health Behaviour Research Program. She has established an international reputation in cancer prevention and early detection, psycho-oncology, doctor-patient communication and cancer survivorship.

#### **A/Prof. Michael Jefford**

Michael is a consultant medical oncologist at Peter MacCallum Cancer Centre, Clinical Consultant with the Cancer Information and Support Service (a unit of Cancer Council Victoria) and is a Principal Fellow with the University of Melbourne. He is Director of

the newly established Australian Cancer Survivorship Centre. His clinical practice, and part of his clinical research, focuses on the management of people with gastrointestinal cancers.

#### **A/Prof. Janette Vardy**

Janette is the Chair of the PoCoG Scientific Advisory Committee, a medical oncologist, working as a clinician researcher at the Sydney Cancer Centre and The University of Sydney. Her research interests include psycho-oncology, quality of life, cognitive impairment in cancer patients and physical activity in cancer patients.

## Research presenters

#### **Dr Vanessa Beesley**

Dr Vanessa Beesley is an NHMRC Post-Doctoral Fellow based at Queensland Institute of Medical Research. Vanessa specialises in cancer survivorship research. She is involved in a number of projects looking at the health-related outcome of people with ovarian, endometrial, pancreatic and colo-rectal cancer, and also Indigenous people with a range of cancer diagnoses.

#### **Ms Rebecca Bergin**

Rebecca Bergin is a member of the department of Nursing and Supportive Care Research at the Peter MacCallum Cancer Centre. She has an honours degree in biochemistry and molecular biology from Melbourne University, and for the past year and a half has worked as project co-ordinator and research assistant on a number of supportive care intervention trials.

#### **Dr Ben Britton**

*Clinical & Health Psychologist, Psycho-Oncology Service, Calvary Mater Newcastle.*

Dr Britton has worked in Psycho-Oncology since 2005 and likes translational research and sea kayaking.

#### **Dr Kerrie Clover**

Dr Clover has a PhD in Behavioural Science in Relation to Medicine and is currently undertaking a Masters of Clinical Psychology. She is the Research Manager for the Psycho-Oncology Service at a major regional cancer centre, the Calvary Mater hospital, in Newcastle, NSW. She has led a program of screening for pain and distress over the past three

years

#### **A/Prof. Gail Garvey**

Associate Professor Gail Garvey is the Lab Head, Indigenous Health Research at Queensland Institute of Medical Research.

She is currently leading a study to validate the Supportive Care Needs Survey for Australian Indigenous Cancer Patients that her team developed for Indigenous cancer patients. Her team is also exploring the different ways we can better meet the needs of Indigenous cancer patients though piloting an Indigenous cancer patient navigator.

#### **Ms Jane Hayman**

Jane Hayman is a PhD student in the School of Psychology at Monash University. Her research investigates the implementation of decision aids for bowel cancer screening and examines issues surrounding informed choice and screening. Until recently Jane was employed at the Cancer Council Victoria where she managed a variety of research projects involving cancer patients over a 9 year period.

#### **Mr Kelvin Koay**

Mr Kelvin Koay, Medical Student from University of Melbourne. Kelvin did his Advanced Medical Science research on health literacy at Peter MacCallum Cancer Centre, under the supervision of A/Prof Michael Jefford and A/Prof Penny Schofield.

#### **Dr Sylvie Lambert**

Dr Lambert is a post-doctoral research fellow with the Centre of Health Research and Psycho-Oncology (CHERP) the behavioural research unit of the Cancer Council New South Wales, based at the University of Newcastle. She obtained her PhD from McGill University, Montreal in 2008 and moved to Australia 1.5 years ago and is currently working on a range of studies, including CHERP's longitudinal partners and caregivers well-being study.

#### **Ms Mirela Matthews**

*Quality and Projects Manager, North Eastern Metropolitan Integrated Cancer Services (NEMICS).*

Mirela is an occupational therapist by training and most recently has been working in service improvement. She also holds the degree of Master of Social Health from the University of Melbourne.

#### **Mr Ben Smith**

Ben Smith is a 2nd year PhD student at the Psycho-oncology Co-operative Research Group, The University of Sydney. Prior to commencing his PhD Ben spent two years working on a variety of psycho-oncology research projects at the Centre for Medical Psychology and Evidence-based Decision-making.

#### **Ms Tara Stern,**

*Clinical Psychologist, St Vincent's Hospital, Sydney.*

Tara specialises in the psychological assessment and therapy of cancer patients, and their family members and carers. She has been working with this population since 2004.

#### **Prof. Jane Ussher and**

#### **A/Prof. Janette Perz**

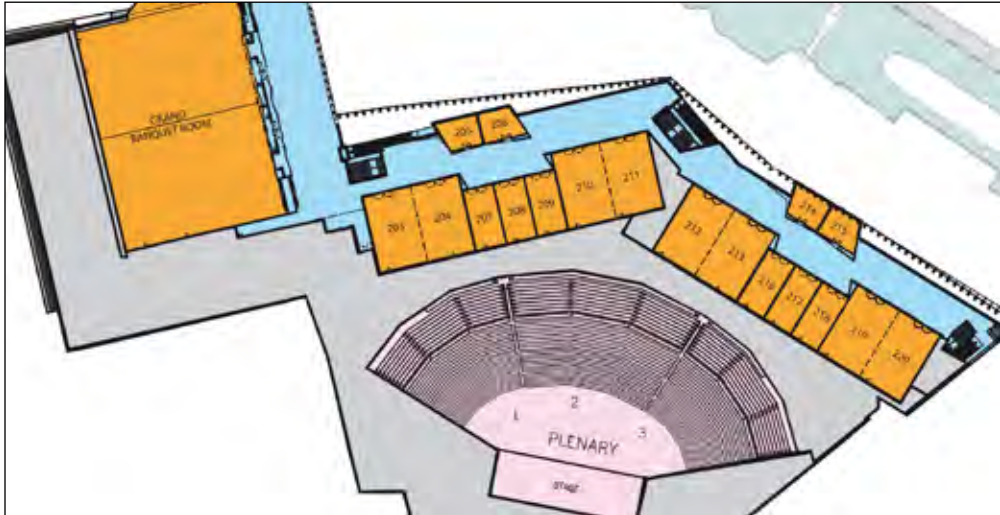
Jane Ussher is Professor of Women's Health Psychology, and Janette Perz is Associate Professor, in the Gender, Culture and Health Research Unit, School of Psychology, University of Western Sydney. Both speakers have research expertise in the gendered experience of health, including cancer carers, cancer and sexuality, and in a forthcoming project, the construction and experience of fertility in the context of cancer.

#### **Dr Claire Wakefield**

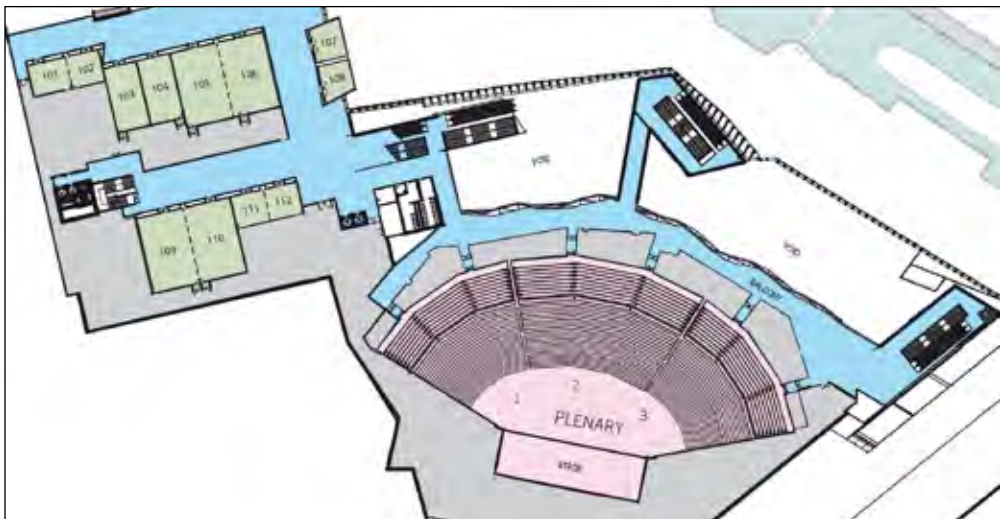
Dr Wakefield is an NHMRC Postdoctoral Clinical Research Fellow and the Program Leader of the Behavioural Sciences Unit in the Centre for Children's Cancer and Blood Disorders at Sydney Children's Hospital. She has a background in conducting psychological research involving cancer and families, especially research involving families with a child with cancer and families at increased risk of hereditary cancer.

# Melbourne Convention and Exhibition Centre VENUE PLAN

Level 2



Level 1



Ground Floor

