Psycho-oncology Co-operative Research Group

THE AUSTRALIAN PSYCHOSOCIAL ONCOLOGY SOCIETY INC

Psycho-oncology partnerships against cancer: Bridging gaps, breaking barriers

OZPOS and PoCoG Psycho-oncology Professional Day
14 November 2011

Final Report

Prepared by Monica Nou

and the PoCoG Executive Office

AN AFFILIATE OF THE UNIVERSITY OF SYDNEY

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PoCoG Publication Number: EO-AR-120130

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1. Executive summary

The third OZPOS/PoCoG Professional Day was held immediately prior to the COSA 2011 ASM in Perth, attracting over 70 registrants. The broad aims of the day allow oral presentation of emerging research not being presented in the ASM program; provide opportunities for networking and discussion of strategies of clinical pathways to support successful implementation of routine screening for distress.

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

The program comprised of a plenary session, one panel discussion, one consensus workshop and a session of research presentations.

The theme of the meeting was “Partnerships against cancer – bridging gaps, breaking barriers”, bringing together some of our top psycho-oncologists to provide a forum for clinical referral pathways for managing psychological distress across the cancer journey and joining with the Australian and New Zealand Urogenital and Prostate Cancer trials group (ANZUP) for a highly anticipated panel discussion on psychosocial aspects of cancers below the belt.

A total of 74 individuals registered through ASN conferences in conjunction with their registration for the COSA ASM and 71 attended the Psycho-oncology Professional Day. The attendees were predominantly Australian psycho-oncology researchers and clinicians, nurses, social workers, oncologists, health professionals and others with an interest in psycho-oncology.

The professional day overall was very highly rated with over 85 percent of participants rating it as either very good or excellent. Other general aspects 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. All of the respondents said that they would attend future professional days

The third 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.

2. Introduction

The third OZPOS/PoCoG Professional Day was held immediately prior to the COSA 2011 ASM in Perth, attracting over 70 registrants. The broad aims of the day allow oral presentation of emerging research not being presented in the ASM program; provide opportunities for networking and discussion of strategies of clinical pathways to support successful implementation of routine screening for distress.

The theme of the meeting was “Partnerships against cancer – bridging gaps, breaking barriers.” and brought together some of our top psycho-oncologists to provide a forum for professional development, drawing on the expertise of a number of Australian and international speakers.

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

In conjunction with their registration for the COSA ASM, 74 individuals registered through ASN conferences and 71 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 attendee profile differed from previous year in that it comprised a very wide range of professional disciplines and represented a large number of organisations. It is worth noting that many of the attendees were not necessarily the intended target of the Psycho-Oncology professional day.

4. Professional Day Summary

The Professional Day program comprised a plenary session, one panel discussion, one consensus workshop and a session of research presentations.

4.1. Plenary session

The plenary session was entitled *Psycho-oncology perspectives across the cancer journey*. The session comprised of three presentations given by Prof. Patsy Yates, Prof. Afaf Girgis and Dr Catherine Burns. The presentations outlined psychosocial issues across the disciplines. The first speaker, Prof. Yates discussed the development and piloting of a nurse-lead cancer survivorship care and management plan. Prof. Girgis, a behavioural scientist, reported on persistent trajectories of anxiety and depression in cancer patients over the first two years post-diagnosis. Dr Burns, a social worker, reported findings from a population study of hands-on care givers at the end of life.

4.2. Panel discussion

A joint panel discussion with ANZUP entitled “*Below the belt; What are we missing in caring for GU patients?”* was chaired by Professor Jane Turner. This session brought together participants from the ANZUP & COSA Urologic Oncology Group Clinical Professional Day and OZPOS & PoCoG Psycho-oncology Professional Day to focus on psychosocial needs of patients with urogenital cancers. Expert clinicians and researchers provided participants with an overview of the latest evidence about psychosocial aspects of prostate and testicular cancer and a multidisciplinary panel led the discussion of about complex clinical issues.

Introductory presentations were given by Addie Wootten and Ben Smith. The discussion panel members were A/Prof Mark Frydenberg (Uro-oncology surgeon), Ms Kim Hobbs (Oncology social worker), Dr Siobhan Ng (Medical Oncologist), Clinical Prof Nigel Spry (Radiation Oncologist), Dr Isabel White (Clinical academic, Cancer nursing).and Dr Addie Wootten (Clinical Psychologist)

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

4.3. Clinical pathways consensus workshops

This session provided the opportunity for participants to hear the summary of evidence in this area of research as well as approaches to implementation. Participants were given the opportunity to work in small groups on developing clinical pathways for managing anxiety and depression. This session was chaired by Professor Phyllis Butow.

Existing international guidelines and models of care were reviewed, and workshop delegates discussed options for the Australian setting. The delegates agreed that routine screening for psychosocial distress in people with cancer should be introduced in Australia, and that adequate training and education should be provided to health professionals to facilitate identification and management of at-risk individuals. The availability of a clinical pathway would assist in advocating for routine screening, given that a process would be in place to manage patients once they had been identified. The clinical pathway would need to be flexible to account for different models of care in tertiary, rural and private hospitals, and to facilitate involvement of the primary care sector. There was consensus that this work should continue. OZPOS and PoCoG plan to draft a set of guidelines based on the outcomes of the workshop. These will be made available to the broader psycho-social community for comment and input.

4.4. Research presentations

From the poster abstracts submitted under the title: *Vulnerable groups – Bridging gaps, breaking barriers,* 5 oral presentations were selected. The session was chaired by Dr Toni Musiello. The presenters were Joanne Shaw, Heather Lane, Michelle Peate and Jordana McLoone

Details of the presentations in this session 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 74 registrants, 27 (36 percent) participated in the feedback survey, while 5 of these participants did not complete the questionnaire. The number of respondents who indicated that they were members of COSA was 19 and of those, 4 indicated membership of OZPOS, 1 indicated membership of OSWA, 4 – membership of CNSA. A total of 18 indicated membership of PoCoG. Approximately 42 percent of the respondents indicated that their primary occupation was in Psycho-oncology research and 14 percent nominated nursing. Other primary roles included psychosocial clinician, oncologist and social worker

The professional day overall was very highly rated with over 85 percent of participants rating it as either very good or excellent. Other general aspects 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. All of the respondents indicated that they would attend future professional days

Table 1 shows topics for future research sessions and workshops as suggested by the respondents.

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

Interventions aimed at improving health behaviours or lifestyle factors for cancer survivors.
Supportive care : e.g. exercise nutrition, faith, hope, promotion
Developing partnerships and pathways with the non-government sector in providing psychosocial services to people affected by cancer (eg Cancer Councils, Leukaemia Foundation, Canteen, etc)
Psycho-oncology and genomics/ sequencing

Summaries of evaluation of individual sessions are provided in sections 5.1 – 4.5 below. Respondents were asked to rate various aspects of each session. These included:

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

5.1. Plenary session

Over 68 percent of respondents who attended the plenary session rated the overall session either very good or excellent. The relevance and educational value of the session was rated highly. Only two comments were offered and these related specifically to the individual presentations.

5.2. Panel Discussion – "Below the belt: what are we missing in caring for GU patients?"

Session length, overall quality, relevance and informative/educational value were all rated excellent or very good. Over 70 percent of the respondents agreed that they would like panel discussions like this at future meetings. This does not include participants registered for the ANZUP clinical day. Comments from respondents were in regards to the timing, many felt there was not enough time for discussion and audience participation.

5.3. Clinical Pathways Consensus Workshop

The number of survey respondents who attended the Clinical pathways consensus workshop was 22. On average, over half of the respondents rated the format and length, materials, general discussion as well the facilitator as either, very good or excellent. Three-quarters of the respondents rated the session as relevant to their skills base. General comments from participants were related to the time frame and group size. Respondents felt that this session could have easily been a half or a full day session and that the group was too large for everyone to participate.

5.4. Research Presentations

This session was rated highly by respondents for all questions relating to this session and 20 of the survey respondents attended the research session.

83 percent of the respondents rated the overall quality and relevance of the presentations as very good or excellent. A further 77 percent of respondents rated the educational/informative value to very good or excellent.

80 percent of those who responded said it was either important or very important for members to have an opportunity to present their abstracts outside the COSA ASM.

6. Outcomes

The third 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 theme of the meeting was *"Partnerships against cancer – bridging gaps, breaking barriers"*, The event successfully engaged researchers by giving them an opportunity to present and receive feedback about their work and establish more formal links with clinicians and other researchers.

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

9. Appendix

OZPOS and PoCoG Psycho-Oncology Professional Day Detailed Program

Psycho-oncology Partnerships Against Cancer – Bridging Gaps, Breaking Barriers

14 November 2011
Perth Convention & Exhibition Centre

The OZPOS & PoCoG Psycho-oncology Professional Day 2011 is jointly funded by COSA and PoCoG.
PoCoG received funding for this event from the Australian Government through Cancer Australia

WELCOME

Welcome to the third OZPOS and PoCoG Psycho-oncology Professional Day 2011: Psycho-oncology Partnerships Against Cancer. This year's program focuses on bridging gaps and breaking barriers. We are bringing together some of our top psycho-oncologists to provide a forum for clinical referral pathways for managing psychological distress across the cancer journey and joining with the Australian and New Zealand Urogenital and Prostate Cancer trials group (ANZUP) for a highly anticipated panel discussion on psychosocial aspects of cancers below the belt.

We hope you will find our program to be stimulating and educational.

Dr Haryana Dhillon
President, The Australian Psychosocial Oncology Society Inc. (OZPOS)
Meeting convenor

Phyllis Butow

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

Meeting convenor

PROGRAM AT A GLANCE

All sessions will be held in Meeting Room 1 on Level 2

9.00 – 10.30	Plenary session PSYCHO-ONCOLOGY PERSPECTIVES ACROSS THE CANCER JOURNEY **Chair:** A/Prof. Janette Vardy **Patsy Yates** Development, implementation and evaluation of a cancer survivor self-management care plan **Afaf Girgis** Anxiety and depression among caregivers of cancer survivors: Adjustment trajectories over the first two years post survivor diagnosis **Catherine Burns** The Invisible Network of ‘Hands On’ Caregivers at the End of Life - findings from a population study
10.30 – 11.00	Morning tea
11.00 - 12.30	Joint session with ANZUP: Panel Discussion BELOW THE BELT: WHAT ARE WE MISSING IN CARING FOR GU PATIENTS? This joint session will bring together participants from the ANZUP & COSA Urologic Oncology Group Clinical Professional Day and OZPOS & PoCoG Psycho-oncology Professional Day to focus on psychosocial needs of patients with urogenital cancers. Expert clinicians and researchers will provide participants with an overview of the latest evidence about psychosocial aspects of prostate and testicular cancer and a multidisciplinary panel will lead the discussion of about complex clinical issues. **Chair:** Prof. Jane Turner
12.30 - 12.50	PoCoG Annual General Meeting. Meeting Room 1
12.50-13-15	Lunch
13.15 -14.45	Clinical pathways consensus workshop: CLINICAL PATHWAYS FOR MANAGING ANXIETY AND DEPRESSION IN CANCER CARE This session will provide the opportunity for participants to hear the summary of evidence in this area of research as well as approaches in implementation. Participants will be given the opportunity to work in small groups to work on developing clinical pathways for managing anxiety and depression. **Chair:** Prof. Phyllis Butow
14.45 - 15.00	Afternoon tea

15.00 - 16.30 **Research presentations:**
VULNERABLE GROUPS - BRIDGING GAPS, BREAKING BARRIERS
Chair: Dr Toni Musiello

Joanne Shaw
Improving psychosocial outcomes for cancer carers: An interview study

Carolyn Lethborg
Understanding the supportive and palliative care needs of people with primary malignant glioma and their carers

Heather Lane
Exploration of the experiences and decision making of older people with cancer

Michelle Peate
The assessment of fertility-related knowledge and decision-making preferences around diagnosis and the prospective evaluation of a fertility-related decision aid in young women with early breast cancer

Jordana McLoone
Melanoma risk, clinical care and patients' fears of melanoma recurrence: what is the interplay between these factors?

16.45 - 18.15 **Clinical research idea starters' workshop**
Hosted by COSA
This workshop will help budding clinician-researchers from all health-care professions to generate ideas and turn them into persuasive concept outlines and applications, for example those needed for ethics approval and to participate in Protocol Development Workshops like ACORD 2012!

Plenary session
PSYCHO-ONCOLOGY PERSPECTIVES ACROSS THE CANCER JOURNEY

Chair: A/Prof. Janette Vardy

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

DEVELOPMENT, IMPLEMENTATION AND EVALUATION OF A CANCER SURVIVOR SELF-MANAGEMENT CARE PLAN

COSA ASM abstract no. 312

P. Yates , A. McCarthy, D. Anderson, G. Salkield, H. Skerman, E. Walpole, C. Aguero, E. Mile

Aim: There is a growing population of people with cancer who experience physiological and psychological effects that persist long after treatment is complete. Interventions that enhance survivors' self-management abilities might help offset these effects. The aim of this pilot study was to develop, implement and evaluate interventions tailored to assist patients to manage post-treatment health issues effectively.

Method: In this pre-post intervention cohort study, participants were recruited on completion of cancer treatment. Participants recruited pre-implementation, who received usual care, comprised the control group. Participants recruited later formed the intervention group. In the intervention group, the Cancer Care Coordinator developed an individualised, structured Cancer Survivor Self-management Care Plan. Participants were interviewed on completion of treatment (baseline) and at three months. Assessments concerned health needs (CaSUN), self-efficacy in adjusting and coping with cancer and health-related quality of life (FACIT-B or FACT-C). The impact of the intervention was determined by independent t-tests of change scores.

Results: The intervention (n=32) and control groups (n=35) were comparable on demographic and clinical characteristics. Sample mean age was 54 ± 10 years. Cancer diagnoses were breast (82%) and colorectal (18%). Statistically significant differences ($p < .05$) indicated improvement in the intervention group for: (a) functional well-being, from the FACIT, (Control: M= - 0.69, SE= 0.91; Intervention: M= 3.04, SE= 1.13); and (b) self-efficacy in maintaining social relationships, (Control: M= - 0.333, SE=0.33; Intervention: M= 0.621, SE= 0.27). No significant differences were found in health needs, other subscales of quality of life, the extent and number of strategies used in coping and adjusting to cancer and in other domains of self-efficacy.

Conclusions: While the results should be interpreted with caution, due to the non-randomised nature of the study and the small sample size, they indicate the potential benefits of tailored self-management interventions warrant further investigation in this context.

PROF. PATSY YATES

Patsy is a Professor with the School of Nursing and Institute of Health and Biomedical Innovation at Queensland University of Technology. She is jointly appointed as Director for Queensland Health's Centre for Palliative Care Research and Education, a statewide service that was established to enhance palliative care services in Queensland through education and research.

ANXIETY AND DEPRESSION AMONG CAREGIVERS OF CANCER SURVIVORS: ADJUSTMENT TRAJECTORIES OVER THE FIRST TWO YEARS POST SURVIVOR DIAGNOSIS

S. Lambert, A. Girgis, B. Jones, C. Lecathelinai

AIMS: To: 1) identify distinct trajectories of anxiety and depression in caregivers of cancer survivors within the first two years post diagnosis and 2) explore the potential variables associated with these trajectories.

METHODS: Partners and caregivers were identified through a population-based sample of cancer survivors participating in the Cancer Survival Study. Participants completed a self-report survey at approximately six (n=547), 12 (n=519), and 24 (n=443) months post survivor diagnosis, which measured the primary outcomes of anxiety and depression as well as key demographics and psychosocial variables (e.g., social support). To identify the trajectories of anxiety and distress, data were analysed using SAS finite mixture model procedure called TRAJ. Associations between the trajectories and selected variables were tested using chi-square analyses for categorical data and ANOVA for continuous data.

RESULTS: For anxiety, the largest group of participants experienced no anxiety across time; however, two additional groups of participants experienced borderline anxiety across time (33.13%) or chronic, clinical anxiety (11.31%) across time. For depression, one group of participants experienced no depression across time; but a second group was consistently near borderline depression across time a third group showed chronic, borderline depression. Psychosocial variables associated with caregivers' course of anxiety and depression included caregiver burden, physical quality of life, social support and coping.

CONCLUSION: This analysis confirms that the course of anxiety and depression differs across caregivers. Findings challenge the assumption that prevalence of anxiety and depression among partners and caregivers decreases over the first year post-diagnosis and highlight that some experienced chronic anxiety or depression across time. Although many partners and caregivers adjust well to the cancer diagnosis, a proportion report anxiety or depression across time points, emphasising the importance of periodic screening for distress and sustained intervention for partners and caregivers.

PROF. AFAF GIRGIS

Afaf Girgis is the Executive Director of the Translational Cancer Research Unit at the Ingham Institute for Applied Medical Research, UNSW. She has spent more than two decades focusing on psycho-oncology research, with a growing focus on assisting cancer caregivers and translational cancer research.

THE INVISIBLE NETWORK OF 'HANDS ON' CAREGIVERS AT THE END OF LIFE

COSA ASM abstract no. 386

C. M. Burns, D. C. Currow, A. P. Abernethy

Aims: Most caregiver palliative care research relies on clinical studies using reports from spouses and/or adult daughters. This population study seeks to explore the nature of bereavement over the life course and examine caregiver activity within this setting.

Methods: An Australian study conducted an annual randomized health population survey (n=23,706) over a 7 year period to obtain a sample of self-identifying bereaved (n=7,915). 33% adults indicated someone close to them died of a 'life limiting illness' in the previous five years. This group was closely representative of the total population in most key socio-demographic details including gender, marital status, income, occupation, place of residence and birth.

Findings: People of all ages indicated they undertook 'hands on' care at the end of life. They were related to the deceased either as close family, that is a spouse, parent or child or as a sibling, extended family member or a friend. Most (80%) with a life limiting disease had a cancer diagnosis. The core group of 'active caregivers' did so on a daily or intermittent basis (22%), with a further 7% engaged on a rare basis. People married for a long time sought to care for their spouses till death including some people aged over 80 years. Surprisingly, 14% of active caregivers were young, aged between 15 and 29 years. A distinctive profile based on availability drove caregiving amongst the middle years. Females most likely to provide daily 'hands on' care had frequently never married or were widowed. Siblings, extended family members and friends accounted for more than half (n=1,222) of the 2,028 respondents.

Conclusions: This substantial network of supportive caregivers mainly invisible to the health team provides an immediate challenge to current practice. Changes are urgently needed identify the extent of potential social support that could be an important resource for patient end of life planning and care.

DR CATHERINE BURNS

Dr Catherine (Kate) Burns is an academic social worker, Discipline Convenor and Senior Lecturer in Social Work School of Humanities and Social Science at the University of Newcastle and Adjunct Senior Research Fellow in the School of Medicine at Flinders University.

Joint session with ANZUP: Panel Discussion

BELOW THE BELT: WHAT ARE WE MISSING IN CARING FOR GU PATIENTS?

CHAIR: A/PROF. Jane Turner

Jane Turner 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.

ORDER OF SESSION

INTRODUCTORY PRESENTATIONS

Addie Wootten: What is the evidence about prostate cancer in terms of psychosocial issues and interventions?
Ben Smith: Overview of key issues pertaining to patients with testicular cancer

PANEL DISCUSSION

Discussion of five clinical case vignettes

SUMMARY AND WRAP UP

EVALUATION

PRESENTERS

MR BEN SMITH

Behavioural scientist

Mr Smith is currently completing his PhD in Psychology focusing on the psychosocial sequalae of testicular cancer, in a collaboration between the Psycho-oncology Co-operative Research Group (PoCoG) and the Australian and New Zealand Urogenital and Prostate Cancer Trials Group (ANZUP). Prior to commencing this study, he worked on a variety of psycho-oncology research projects in the Centre for Medical Psychology and Evidence-based Decision-making (CeMPED) at The University of Sydney.

DR ADDIE WOOTTEN

Clinical Psychologist

Dr Addie Wootten is a clinical psychologist working both in clinical and research roles. Working at the Australian Prostate Cancer Research Centre Epworth she is responsible for conducting psychosocial research with men who have prostate cancer and their families. Her clinical work spans the continuum of prostate cancer, from initial diagnosis to end of life issues. Addie is the convenor of the Australasian Prostate Cancer Conference Psycho-Oncology Meeting held annually in Melbourne.

THE DISCUSSION PANEL

A/PROF. MARK FRYDENBERG

Uro-oncology surgeon

Mark Frydenberg obtained his FRACS in urologic surgery in 1990, and then completed a uro-oncology subspecialised fellowship at the Mayo Clinic, Minnesota, USA . In 1997, he was appointed as Chairman, Department of Urology, Monash Medical Centre, a position he still holds ; and was also appointed as a clinical associate professor in the Department of Surgery, Faculty of Medicine, Monash University . He is currently the clinical chairman, of the Prostate cancer research program, Department of Anatomy, Monash University ; chairman of the Uro-oncology special advisory group of the Urological Society of Australia and New Zealand, inaugural chairman of Institute of Specialty Surgery, Epworth Health and a board member of Andrology Australia . He is on the editorial board of BJU Int, and the International Brazilian Journal of Urology, and reviews regularly for these journals, as well as Urologic Oncology, Urology and Australian journals such as Medical Journal of Australia and the Australian and New Zealand Journal of Surgery.

MS KIM HOBBS

Oncology social worker

Over the course of a long career in Oncology Social Work, Kim has extensive clinical experience in a number of different cancer settings. In addition to clinical work, she has been involved in the development of information and training resources for both cancer patients and health professionals. She has a particular interest in the psychosexual outcomes for people with cancer and their partners and is a Principal Investigator on a current ARC Linkage Grant, Multiple perspectives on sexuality and intimacy post-cancer, leading to the development and evaluation of supportive interventions.

DR SIOBHAN NG

Medical oncologist

Siobhan Ng is a medical oncologist with focus in Uro-Oncology at Sir Charles Gairdner and the Bendat Cancer Centre, St John of God hospital Subiaco, WA. She has extensive Clinical Trial involvement for the treatment of prostate and renal cancer.

CLIN. PROF. NIGEL SPRY

Radiation oncologist

Nigel Spry is a busy practicing clinician with a comprehensive experience in cancer medicine. He is a Senior Specialist in Radiation Oncology at the Sir Charles Gairdner Hospital, Perth and recently he has been appointed Clinical Professor, School of Pharmacology and Medicine, University of Western Australia. He is an enthusiastic researcher who employs an eclectic approach. He has a long experience in collaborative clinical trial involvement and was a co-founder of the Trans-Tasman Radiation Oncology Group (TROG) in 1987, which is now a major radiation research group in Australia and New Zealand. He has been centrally involved in studies assessing curative and palliative outcomes as well as toxicity reduction initiatives. He participates on quality assurance and trial audit panels. He strongly pushes for cross discipline involvement in the development and running of clinical studies.

DR ISABEL WHITE

Clinical academic, cancer nursing

Isabel is a clinical academic in cancer nursing, holding both academic and clinical posts in the university and health service sectors in London. She has a dual professional background in cancer nursing from 1984 and psychosexual therapy since 2001 and obtained her PhD in 2008. She is a member of the Department of Health’s (England) National Cancer Survivorship Initiative (NCSI) late effects sub-group and her work contributes to a programme of research focused on the assessment and management of treatment consequences arising from pelvic cancer (NCSI). She is a member of the Consequences of Cancer Treatment Collaborative (CCat) formed in 2009 in association with the NCSI and Macmillan Cancer Support. Her clinical and research interests focus specifically on the assessment and management of treatment-induced sexual difficulties and the development of sexual rehabilitation strategies and she is secretary of the International Society of Sexuality and Cancer (ISSC).

DR ADDIE WOOTTEN

Clinical Psychologist

Dr Addie Wootten is a clinical psychologist working both in clinical and research roles. Working at the Australian Prostate Cancer Research Centre Epworth she is responsible for conducting psychosocial research with men who have prostate cancer and their families. Her clinical work spans the continuum of prostate cancer, from initial diagnosis to end of life issues. Addie is the convenor of the Australasian Prostate Cancer Conference Psycho-Oncology Meeting held annually in Melbourne.

PoCoG
ANNUAL GENERAL MEETING 2011

Monday 14 November 2011, 12:30 – 12: 50pm, Meeting Room 1
Perth Convention and Exhibition Centre

AGENDA

1. **Welcome**
   Professor Phyllis Butow, PoCoG Chair
2. **Report on the new Quality Assurance processes at PoCoG**
   Dr Michelle Peate, Research Project Manager
3. **Report from the WA interest group**
   Dr Toni Musiello, Dr Suzie Brans
4. **Report from the SA interest group**
   Caroline Miller
5. **IPOS World Congress 2012**
6. **Wrap up and questions**

Clinical pathways consensus workshop: CLINICAL PATHWAYS FOR MANAGING ANXIETY AND DEPRESSION IN CANCER CARE

CHAIR: 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.

WORKSHOP AIMS AND OUTLINE

The aim of this workshop is to provide an overview of existing Clinical Practical Guidelines for the management of psychological distress (anxiety and depression) in the context of cancer care. This workshop also provides an opportunity for participants to discuss some case studies and to contribute to identifying potential solutions for optimising clinical referral pathways for managing anxiety and depression in the Australian context.

The goal of the workshop is to gain some consensus around referral pathways and potential solutions to ease the gap between optimal clinical pathways and the current reality.

It is hoped that the outcomes of the workshop will directly inform the ongoing translational research agenda focusing on implementing routine screening for distress and care pathways to improve psycho-social care and outcomes for cancer patients.

The workshop outline is as follows:

13.15-13.45: Prof Phyllis Butow: Introduction and overview of existing guidelines

13.45-14.15: Small group work

14.15-14.45: Group feedback and discussion led by Phyllis Butow

SMALL GROUP WORK

Group 1: Facilitators: Jane Turner and Ben Britton

Group 2: Facilitators: Cathy Mason and Cath Adams

Group 3: Facilitators: Haryana Dhillon and Toni Musiello

Group 4: Facilitators: Kim Hobbs and Melanie Price

Research presentations:
VULNERABLE GROUPS - BRIDGING GAPS, BREAKING BARRIERS

Chair: Dr Toni Musiello

Toni is a research psychologist and a clinician working at the QEII Medical Centre, The University of Western Australia. She is also the convenor of PoCoG's WA interest group. Her key research interests include the psycho-oncology of breast cancer, health behaviour change, addiction, and the effect of paediatric general anaesthesia upon cognitive function.

IMPROVING PSYCHOSOCIAL OUTCOMES FOR CANCER CARERS: AN INTERVIEW STUDY

COSA ASM abstract no. 323

J. Shaw, J. Harrison, J. Young, P. Butow, C. Sandroussi, D. Martin, M. Solomon

Background: Patients with upper gastrointestinal (UGI) cancers have a poor prognosis. Disease and treatment side effects have a significant negative impact on the quality of remaining life. Family members are also at high risk of significant distress and carer burden. The early post-operative period is a time of transition of care, patients have advanced disease and the carer is new to the caring role, established risk factors for poor carer outcomes. However a pilot of a supportive care telephone intervention conducted by this research group found poor uptake of the intervention by carers. Reluctance to participate was attributed to caregivers' role perception.

Aims: This study aimed to gather information regarding family members' perceptions of their role as a caregiver and identify the needs and potential barriers to acceptance of supportive care at two points: within three weeks of diagnosis and surgery and three months later.

Methods and results: Family caregivers of newly diagnosed post-surgical UGI cancer patients were recruited. Semi-structured telephone interviews were conducted and analysed using a constant comparative approach. Sampling was discontinued when information redundancy was achieved. 15 family members participated in the first interview and 8 agreed to a second interview. Patient prognosis determined willingness to participate in interview two. Initially families described their role as one of patient support. By 3 months, patient health status determined role perception. In interview one families highlighted a number of information, medical, practical, relationship and emotional needs. By interview 2, emotional support was the primary concern.

Conclusions: The results of this study have informed the study design and intervention focus of a RCT to determine the effectiveness of a structured telephone intervention to reduce unmet supportive care needs and psychological distress and to improve quality of life of family caregivers of patients with poor prognosis UGI cancer.

DR JOANNE SHAW

Dr Joanne Shaw is a postdoctoral researcher with the Surgical Outcomes Research Centre, a collaborative research group within the University of Sydney School of Public Health and Royal Prince Alfred Hospital. Joanne is currently coordinating an NHMRC-funded study investigating the effectiveness of a telephone-based supportive care intervention for the families of patients diagnosed with poor prognosis upper gastrointestinal cancers.

UNDERSTANDING THE SUPPORTIVE AND PALLIATIVE CARE NEEDS OF PEOPLE WITH PRIMARY MALIGNANT GLIOMA AND THEIR CARERS

COSA ASM abstract no. 245

A. Collins, C. Lethborg, C. Brand, M. Gold, V. Sundararajan, M. Murphy, G. Moore, J. Philip

Objectives: People with primary malignant glioma (PMG) have distinct supportive and palliative care needs which are poorly understood and managed. The aim of this qualitative study was to explore the needs of patients with PMG and their carers to inform the development of a model which seeks to improve quality of care.

Methods: Consecutive patients were approached along with their nominated carers through neurosurgery, oncology and palliative care units of two metropolitan hospitals. Bereaved carers were identified by health care professionals (HCPs) and invited by letter to participate. Semi-structured interviews were conducted by a single interviewer until data saturation. HCPs from two metropolitan hospitals and one community palliative care service were invited to participate in multi-disciplinary focus groups. Interviews and focus groups were recorded and transcribed, and then thematically analysed by three independent researchers. All investigators reviewed the interviews for consistency and cross validation.

Results: Interviews were held with 8 patients, 8 carers, 8 bereaved carers, and 6 focus groups involving 35 HCPs (13 nurses, 11 doctors and 11 allied health clinicians; mean 17 years clinical practice). Carers reported difficulty managing subtle behavioural and personality changes, cognitive decline and poor insight, which were often poorly recognised by others within the health system. Patients described difficulty accessing and navigating complex care services which were often unresponsive. Carers had information needs that sometimes conflicted with patients' needs for hope. HCPs reported difficulty in planning care as fluctuations in functional state were common. Offers of support tended to be reactive and only when patients expressed need or marked disability rather than offered routinely.

Conclusions: Coordination of care through an identifiable, accessible and informed HCP appears critical. This would ensure service and information provision appropriate to disease state, assist navigation through health services and ensure palliative care services are better integrated into patient and family care.

This study was funded by The Victorian Cancer Agency

DR CARRIE LETHBORG

Dr Lethborg is the Clinical Leader, Cancer Social Work, Co-ordinator Psychosocial Cancer Care at St Vincent's Hospital in Melbourne. She has been actively involved with clinical and research programs in cancer for over 20 years.

EXPLORATION OF THE EXPERIENCES AND DECISION MAKING OF OLDER PEOPLE WITH CANCER

COSA ASM abstract no. 272

H. Lane, S. A. McLachlan, J. Philip

Background: Australian society is aging and as cancer incidence increases with age, the care of older people with cancer is a growing concern. Older people have particularities which will impact upon their experience of cancer diagnosis and management. The majority of literature around cancer care, however, focuses on a younger population.

Aims: To explore the experiences, decision making and the impact of age on older people with cancer.

Methods: In this qualitative research, semi structured interviews were conducted with 12 older people with cancer. Interviews were audiotaped and transcribed. Consecutive interviews were continued until saturation of themes occurred. A thematic analysis was undertaken, with two researchers analysing the transcripts separately, to maximise consistency and minimize bias.

Results: While reporting not feeling old and wanting to live, the interviewees simultaneously noted an acceptance of the possibility of dying and felt better equipped than younger people to deal with a cancer diagnosis. They followed their doctor's advice and did not seek information from other sources. While satisfied with the information they received they avoided some negative information. The interviewees did not think their treatment was less than a younger person would receive or feel discriminated against because of their age.

These older people stressed their role in the larger network of family and friends, and their cancer decisions were made taking into account of the needs and views of this network. In this way, family members and friends were integral to care.

Conclusions: An individualistic model of medical care may not be appropriate for older people with cancer, who implicitly include family member needs when making treatment decisions.

DR HEATHER LANE

Dr Heather Lane is a Geriatrician and General Physician with an interest in Palliative Care, who is currently undertaking a PhD at the Centre for Palliative Care, St Vincent's Hospital, Melbourne, exploring the decision-making of older people with cancer.

THE ASSESSMENT OF FERTILITY-RELATED KNOWLEDGE AND DECISION-MAKING PREFERENCES AROUND DIAGNOSIS AND THE PROSPECTIVE EVALUATION OF A FERTILITY-RELATED DECISION AID IN YOUNG WOMEN WITH EARLY BREAST CANCER

COSA ASM abstract no.339

M. Peate, B. Meiser, M. Hickey, C. Saunders, P.s Butow, H. Zorbas, B. C. Cheah, D. Hadzi-Pavlovic, M. Friedlander

Background: Fertility is a priority for many young women with early-stage breast cancer (EBC). Interventions to retain fertility generally need to be accessed before chemotherapy, but women need to know about their options to make informed decisions.

Aims: To assess fertility knowledge and decisional conflict (DC) in young women with newly-diagnosed EBC. To prospectively evaluate, compared to usual care, the efficacy of a fertility-related decision aid (DA).

Methods: 120 recently diagnosed patients aged 18-40 years with EBC, who desired future fertility, were recruited from 19 Australian oncology clinics. Baseline knowledge regarding fertility-related information, DC, and information/decision-making preferences were measured. Participants were allocated to receive either the DA or usual care. The fertility-related DC, decision regret, and patient satisfaction were measured at one and twelve months. Intention-to-treat linear mixed effects modelling examined the effect of the intervention.

Results: Decreased knowledge was associated with increased DC ($p<0.001$). Consideration of IVF was not related to relationship status ($p=0.72$) or desire for children ($p=0.51$). Compared to usual care, women who received the DA had: reduced DC ($p=0.004$) and improved knowledge ($p=0.02$), after adjusting for education, desire for children and baseline uncertainty; reduced decisional regret at one year ($p=0.031$), after adjusting for education; were more satisfied with the information received on the impact of cancer treatment on fertility ($p<0.001$), fertility options ($p=0.005$); and rated it more helpful ($p=0.002$).

Conclusions: Around diagnosis, many young EBC patients have low fertility-related knowledge. Low knowledge is associated with increased DC, which is likely to undermine the quality of decision-making. Neither relationship status nor firm plans regarding future children reliably predict desire to pursue fertility preservation. Compared to usual care, the DA reduced DC, decision regret and increased satisfaction. These findings support the widespread use of this DA shortly after diagnosis for younger EBC patients who have not completed their families.

DR MICHELLE PEATE

Dr Peate is the Research Program Manager for PoCoG. She has been working in psycho-oncology since 2004, and completed her PhD in 2010 through the University of NSW. Her primary research focus is in the psychosocial and reproductive issues of young women with cancer and the psychosocial issues of adolescents and young adults with cancer.

MELANOMA RISK, CLINICAL CARE AND PATIENTS’ FEARS OF MELANOMA RECURRENCE: WHAT IS THE INTERPLAY BETWEEN THESE FACTORS?

COSA ASM abstract no. 337

J. McLoone, N. Kasparian, B. Meiser, P. Butow, K. Barlow-Stewart, M. Charles, G. Mann, S. Menzies

Background: Prognosis for the majority of melanoma patients is favourable, with overall five year survival rates estimated at 98%. Despite excellent survival rates, patients continue to live with an increased risk of developing new primary disease. The prevalence of fear of melanoma recurrence (FOR) among individuals at increased risk of developing new disease has not previously been quantified. This study reports the prevalence of FOR among moderate to high risk melanoma survivors and explores the psychological mechanisms which may moderate these fears.

Method: Participants completed a self-report questionnaire assessing satisfaction with clinical care in relation to melanoma, as well as psychosocial, behavioural, demographic and medical factors. Participants were recruited via the High Risk Clinic, Sydney Melanoma Diagnostic Centre (high-risk group) and the Melanoma Institute Australia (moderate-risk group).

Results: Participants (N=306; 54% high risk; 56% male; mean age 60 years) reported clinically-relevant levels of FOR (74%; n.s. between groups). High-risk (HR) participants reported significantly greater perceived risk of developing a melanoma in the future, compared to moderate-risk participants. HR participants also reported significantly greater satisfaction with clinical care, more frequently endorsed a preference for discussing problems or worries with one’s doctor as a benefit of clinical skin examination (70% versus 56%), and a greater percentage reported that their doctor had provided education regarding sun protection.

Conclusions: Though HR participants perceived their risk of developing melanoma as greater compared to MR participants, their fear of melanoma recurrence remained similar to MR participants. Analysis of the factors moderating HR participants’ FOR have the potential to inform clinical practice and psychosocial support services for individuals at HR of developing melanoma.

DR JORDANA MCLOONE

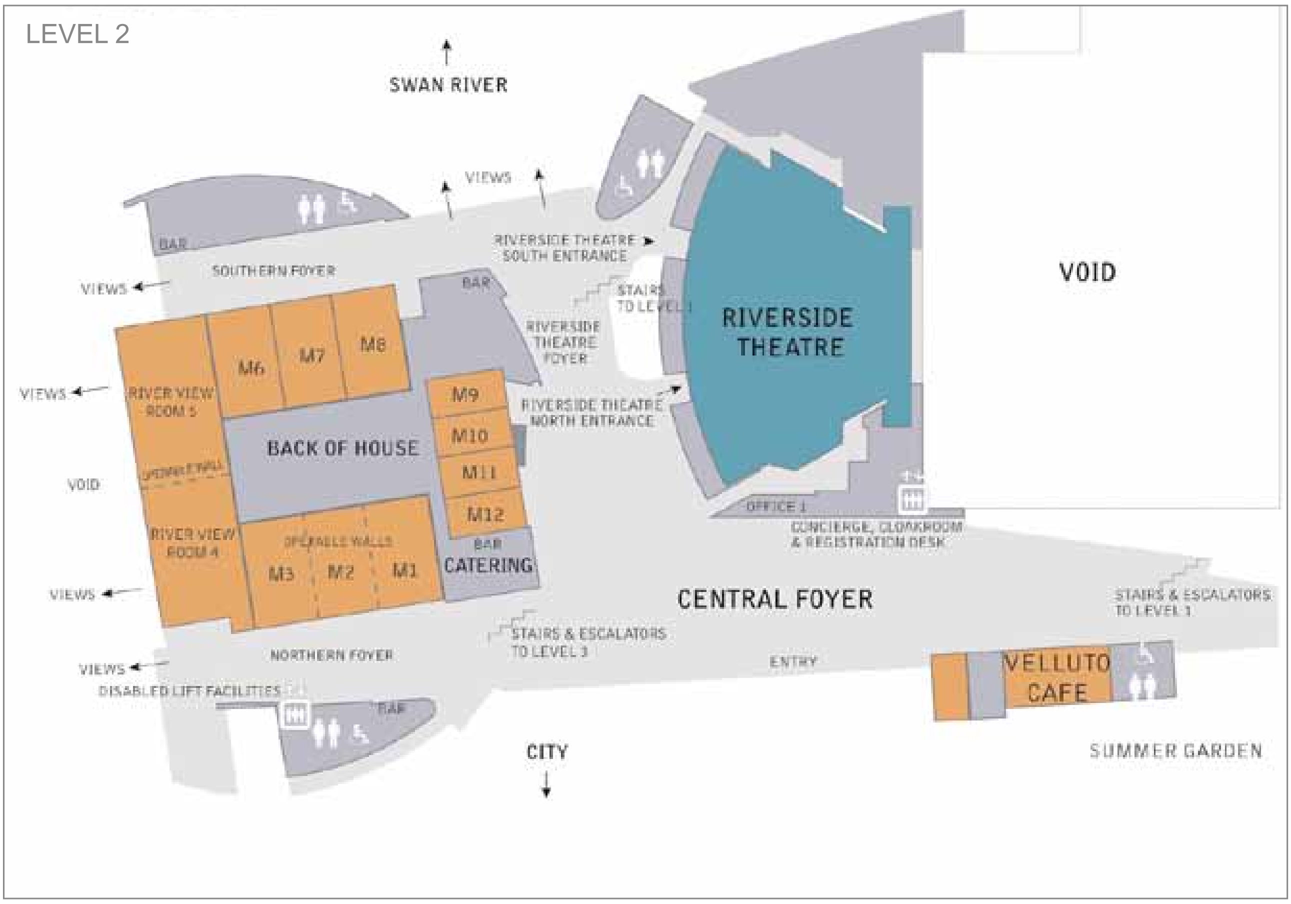
Dr Jordana McLoone is a post-doctoral research associate from the University of NSW. Dr McLoone has a PhD in psychology and has been working in the field of psychooncology for the past 5 years.

Perth Convention and Exhibition Centre

VENUE INFORMATION

Perth Convention and Exhibition Centre is located in the heart of Perth city, adjacent to the Swan River. The location provides quick and easy access to and from the Centre by car, train, bus, taxi and on foot.

OZPOS and PoCoG Psycho-oncology Professional Day 2011: Psycho-Oncology Partnerships Against Cancer Bridging Gaps, Breaking Barriers will be held in Meeting Room 1 on Level 2. Please refer to floor plan for location.



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