Contents

Convenor's Welcome

I am delighted to welcome you to the second Flinders Survivorship Conference.
This year, the Flinders Centre for Innovation in Cancer is partnering with the Clinical Oncology Society of Australia to co-host this event. This exciting partnership will help ensure this conference is closely aligned with the national directions for cancer control and continues to expand its reach and relevance to a diverse range of cancer health professionals, policy makers and to all those affected by cancer.

Following the success of the two previous biennial conferences, the 2017 Flinders COSA Survivorship Conference will bring together a diverse group of clinicians, researchers, policy makers and consumers from Australia and beyond, to learn, to be challenged and to make a lasting impact on the lives of those affected by cancer.

The theme this year is "Cancer Survivorship 2017: Pathways to better policy and practice" which focuses our thinking on how we can translate the growing evidence in this area into day to day applications. We will explore diverse perspectives from Australia, UK, US and countries of our region to identify how collaboratively we can accelerate progress, share learnings and promote best practice. We will explore stories of survivors themselves, and ask some challenging questions like what is survivorship like if it is not life after cancer, but life with cancer? And in the spirit of translating knowledge into practice, we will not just listen and note but reflect, engage and experience what practice of good survivorship is all about.

I hope that you will learn and be inspired; that you will connect with old friends and make many new ones and that you will find some time to enjoy the beauty of our wonderful city and its surrounds.

With best wishes,

Professor Bogda Koczwara
Conference Convenor

Host Organisations

Flinders Centre for Innovation in Cancer

The Flinders Centre for Innovation in Cancer (FCIC)
The FCIC is a leading cancer centre in Australia, housing world-class care and survivorship services alongside innovative cancer prevention and early intervention research. Building on the Flinders Medical Centre's reputation as a leader in compassionate cancer care and the Flinders University's world-class medical research, the FCIC provides an integrated approach to tackling cancer. It is a place where survivorship is not just an ideal but an everyday achievable goal, a place of support and care for all from the point of diagnosis, through treatment and as they continue in life.
http://www.fcic.org.au

Clinical Oncology Society of Australia

Clinical Oncology Society of Australia (COSA)
COSA is the peak national body representing health professionals from all disciplines whose work involves the care of cancer patients. COSA's vision is that all Australians receive quality multidisciplinary cancer care from supported and informed health professionals who work in a multidisciplinary manner.
https://www.cosa.org.au

Committee

Thank you to all the individuals who have made this conference possible, including:

Conference Convenor:

Bogda Koczwara	Flinders Centre for Innovation in Cancer, Flinders University, SA

Program Committee:

Ray Chan	Queensland University of Technology
Chris Christensen	Cancer Voices SA
Nadia Corsini	Cancer Council SA
Haryana Dhillon	University of Sydney
Liz Eakin	University of Queensland
David Joske	Sir Charles Gairdner Hospital, WA
Lee Kennedy	BreaCan, VIC
Bogda Koczwara	Flinders Centre for Innovation in Cancer, Flinders University, SA
Brigid Lynch	Cancer Council VIC
Annie Miller	Cancer Council NSW
Danielle Tindle	Queensland University of Technology
Janette Vardy	University of Sydney
Marie Malica	Clinical Oncology Society of Australia
Fran Doughton	Clinical Oncology Society of Australia

Ashleigh Moore Oration 2017

Ashleigh Moore

The Oration was established to recognise the significant contribution of Ashleigh Moore to the field of cancer survivorship in South Australia and beyond. To commemorate Ashleigh's lasting contribution to the care of those affected by cancer, the Flinders Centre for Innovation in Cancer established the annual Ashleigh Moore Oration to recognise an individual or organisation in Australia who has made an outstanding contribution to the care of cancer survivors through contribution to clinical practice, research, policy, and/or advocacy affecting cancer survivors.

Congratulations to John Stubbs who will be presenting the 2017 Ashleigh Moore Oration on Friday 3 February (which auspiciously marks the third anniversary of Ashleigh's passing).

John Stubbs

Eighteen years ago John was diagnosed with Chronic Myeloid Leukaemia. Following a successful bone marrow transplant in 2001 he became a committed and passionate advocate for people affected by cancer. He holds degrees in Accounting and Arts and is a regular speaker at medical conferences in Australia and internationally about health and cancer policy, advocacy, clinical trials, research and related issues. John was awarded an Honorary Associate of the University of Sydney - School of Medicine in 2009 for work in the promotion of Clinical Trials in Australia and a Recognition Award from the Federal Department of Health in 2011 for – "long standing commitment to advancing the quality of radiation oncology services in this country". He currently holds four Board positions – Cancer Institute NSW, Medical Board of NSW Health Consumers NSW, NSW Illawarra and Shoalhaven Health district as well as a member of 16 Federal and State Government Health and Research Committees. John has contributed to over 40 research papers as an Investigator and Associate Investigator.

Invited Speakers

INTERNATIONAL SPEAKERS

Catherine Alfano
American Cancer Society (ACS)

Catherine M. Alfano, Ph.D. is the Vice President of Survivorship at the American Cancer Society (ACS) where she provides vision and leadership to ACS research, programming, and policy efforts nationwide to improve the lives of cancer survivors. She previously served as Deputy Director of the National Cancer Institute (NCI)'s Office of Cancer Survivorship where she created seminal funding opportunity announcements in cancer survivorship and administered the majority of the NCI grant portfolio of rehabilitation and lifestyle change trials in cancer survivors. Dr. Alfano trained as a rehabilitation psychologist and has focused her career in cancer survivorship. Dr. Alfano earned her PhD in clinical psychology with an emphasis in behavioral medicine from the University of Memphis. Her doctoral work focused on physical activity and health outcomes research and on interventions to help people adopt and maintain a healthy lifestyle. She completed her residency in clinical rehabilitation psychology at the University of Washington Medical Center. Following her residency, she completed a clinical fellowship in oncology at the Seattle Cancer Care Alliance, as well as a post-doctoral research fellowship in Biobehavioral Cancer Prevention and Control at the Fred Hutchinson Cancer Research Center and the University of Washington. Her research interests include optimizing interventions and models of care for cancer rehabilitation and survivorship; healthy behavior change; and the integration of biological and behavioral pathways governing health, aging, and cancer prognosis. She has extensive expertise in population-based prospective cohort studies of cancer survivors and in lifestyle behavior change trials in cancer survivors and in people at heightened risk for cancer. She has authored over 100 peer-reviewed publications and has contributed to several key studies examining the effects of weight and exercise on cancer symptoms, quality of life, and prognosis. Dr. Alfano is a frequent speaker internationally and domestically on cancer rehabilitation, cancer survivorship, and research and policy efforts to create effective efficient and patient-centered care for people living with and beyond cancer. In addition to her work at the American Cancer Society, She is an Adjunct Professor of Oncology at Georgetown University Medical Center. She also holds leadership positions as the Chair of the Cancer Special Interest Group of the Society of Behavioral Medicine and on the Research Task Force of the American Congress of Rehabilitation Medicine's Cancer Networking Group and the American Society of Clinical Oncology's Survivorship Committee.

Jane Maher
Macmillan Cancer Support
Jane Maher has been Chief Medical Officer of the UK charity, Macmillan Cancer Support, since 1999 and now shares the role as Joint CMO with general practitioner, Dr Rosie Loftus, reflecting the growing need for specialists and generalists to work more effectively together. She was an improvement clinical leader for the National Health Service for over ten years and is a consultant clinical oncologist at Mount Vernon Cancer Centre, where she has worked for more than 20 years and during which time she helped develop non surgical oncology services in five district general hospitals. She is an honorary senior clinical lecturer at University College London and Visiting Professor in Cancer and Supportive Care at the Centre for Complexity Management at the University of Hertfordshire. Jane has recently been appointed a non-executive director at The Christie NHS Foundation Trust in Manchester. Jane chaired the Maher Committee for the Department of Health in 1995, led the UK National Audit of Late Effects Pelvic Radiotherapy for the Royal College of Radiologists in 2000 and chaired the National Cancer Survivorship Initiative Consequences of Treatment work stream. She co-founded one of the first Cancer Support and Information services in the UK, winning the Nye Bevan award in 1992 and more than 60 support and information units have been established, based on this model. She is a member of the Older People and Cancer Clinical Advisory Group. She has published widely and is a UK representative for cancer survivorship in Europe and advises on cancer survivorship programmes in Denmark and Canada.

NATIONAL SPEAKERS

Dr Antoinette Anazodo
Sydney Children's and Prince of Wales Hospitals
Antoinette trained in Paediatric and Adolescent Oncology in the United Kingdom and completed her training with a clinical fellowship in the Kids Cancer Centre at Sydney Children's Hospital. During her training and fellowship Antoinette completed a postgraduate diploma in Adolescent Oncology and has developed a comprehensive understanding of the issues specific to AYA patients including best practice for tumour types.
Antoinette was appointed as Director of Adolescent and Young Adult (AYA) Cancer at Sydney Children's and Prince of Wales Hospital in October 2010 and has subsequently developed a comprehensive AYA cancer service across both the paediatric and adult cancer centre. Antoinette's appointment across the paediatric and adult campus has also provided opportunities for clinical and research collaboration between paediatric and adult colleagues especially in the area of oncofertility research.
Dr Anazodo has received a number of awards, including a Champions Award from Prince of Wales Hospital, Pride of Australia award in 2015, Churchill Fellowship in 2015 and nomination for Women of the Year in February 2016 for her work on reproductive concerns in cancer patients. Dr Anazodo is a board member on CanTeen Strategic Advisory Group and the CanTeen Youth Cancer Research Group.
Dr Anazodo is the Chair of the NSW and ACT AYA advisory group since 2011 and a member of the Member of the AYA COSA Steering Group since 2010. Dr Anazodo has been involved in the development of three national AYA guidelines in collaboration with COSA and CanTeen. She is the chair for the updated AYA fertility preservation guidelines and a member of the international working group on fertility preservation and co-chair of the Oncofertility Think Tank. Dr Anazodo has been part of the national leadership group working with national and state partners to develop specialist Youth Cancer Services (YCS) across Australia providing vital treatment and support to young patients. Dr. Anazodo is a member of the AYA working group developing AYA services across Sydney Children's Hospital and Prince of Wales Hospital.

Prof Sanchia Aranda
Cancer Council Australia
Honorary Professor Sanchia Aranda was appointed as CEO of Cancer Council Australia in August 2015. She currently holds academic appointments with the School of Health Sciences, University of Melbourne and the Faculty of Nursing, University of Sydney and is a research fellow at the Peter MacCallum Cancer Centre. She has more than 30 years' experience in cancer control and has held prior roles in healthcare, government and tertiary education. For the last 20 years Sanchia has worked in international cancer control, with 16 years on the board of the International Society of Nurses in Cancer Care, including 4 as President (2006-2010). She is the President-elect for the Union for International Cancer Control and has been on the board of UICC for 5 years. She also served on the Advisory Council for Cancer Australia for 8 years until 2015. Her contributions to cancer control have been recognized nationally and internationally and in 2013 she was named the 4th Peter MacCallum Cancer Centre Distinguished Fellow for her contributions to Cancer Nursing.

Chris Christensen
Cancer Voices SA
Chris Christensen (MEdM, BEd, DipTeach) has worked in policy and leadership positions in the South Australian Public Service including Cabinet and Executive Council, Intergovernmental Relations, Education and Child Development. Chris is a four times survivor of primary peritoneal cancer, first diagnosed in 2010. Her main treatments have included two major operations, two chemotherapy treatments and participation in the ARIEL2 PARP Inhibitor drug trial. Chris is a member of the Cancer

Voices South Australia Executive and was recently appointed as Chair. Cancer Voices South Australia is a volunteer organisation whose purpose is to raise an independent voice to influence the achievement of better outcomes for people affected by cancer. Her areas of interest cover the cancer continuum and include equitable access to holistic, high quality patient centred treatment and ongoing care; consumer voice and engagement in all aspects of cancer services and policy; survivorship; genetics and rare cancers; trials as a treatment option; cancer research; and public education about cancer. Chris has been involved in South Australian Cancer Services committees related to governance, safety and quality and chemotherapy standards. She has advocated for system improvement through survivors as teachers talks and presentations to medical professionals, students and community groups. Chris has been a consumer representative on the Return to Work following a cancer diagnosis and Survivorship Framework projects and has established a Cancer Voices Walking Group which supports her focus on wellness, not just illness.

Mr David 'Tarnda' Copley
Pangula Mannamurna Aboriginal Corporation

David is an Aboriginal man of Kaurna and Peramangk decent and a recognised Elder of the Kaurna & Peramangk Nations of South Australia. David was the 1st Aboriginal person to obtain a Diploma of Applied Science Developmental Disabilities) – South Australian College of Advanced Education. He was also the 3rd Aboriginal man in South Australia to graduate from University with a Bachelor of Nursing (Flinders University) and is the only male Aboriginal Registered Nurse in South Australia to hold Post Graduate qualifications in Mental Health Nursing (Flinders University). David is: a Tobacco Treatment Specialist registered with the Australian Association of Smoking Cessation Professionals; a Delegate of the National Congress of Australia's First People; a member of the Congress of Aboriginal & Torres Strait Islander Nurses; an Executive Board Member of the Australian Association of Smoking Cessation Professionals; an Advisory Board Member of the Centre for Research Excellence in Indigenous Cancer (Discover –TT) Menzies School of Health Research; a member of the Aboriginal Governance Council, South Australian Aboriginal Diabetes Study with SAMHRI; facilitator of Aboriginal Stories of Cancer Survival with Menzies School of Health Research; and a member of the Indigenous Advisory Group, Menzies Cancer Research Group. David's key areas of practice & research are around Aboriginal & Torres Strait Islander Cancer Awareness, Mental Health, Substance misuse and the Social Determinants that impact on these health areas. He is also a survivor of stage 3 Colon Cancer.

Dr Haryana Dhillon
University of Sydney

Haryana is a Research Fellow in Cancer Survivorship at the Centre for Medical Psychology and Evidence-based Decision-making (CeMPED) University of Sydney. She is also a member of the Board and Council of the Clinical Oncology Society of Australia (COSA) and Council, and Chair of the COSA Survivorship Group. Haryana co-leads a Cancer Survivorship Research Group based in the University of Sydney. The Group is supported on peer-reviewed funding, allowing studies in cancer and cognition, physical activity in cancer populations, sleep disturbance and symptom control. She also maintains an active research interest in health literacy, communication in the cancer setting and patient education.

Jenny Donovan
Stylish Notes

Jenny Donovan was previously a senior lecturer in the School of Nursing and Midwifery at Flinders University and more recently in the School of Nursing Charles Darwin University as the postgraduate course coordinator for child and family health nursing in community. Her main research interests focussed on men in families. Prior to her breast cancer diagnosis and re-occurrence Jenny, also a qualified musician, worked as an accompanist for wind, string, brass and voice. She also played for music theatre. After that time, while facing up to her own mortality, Jenny studied and developed aspects of music therapy training and developing therapeutic drumming groups while combining her two professional interests, nursing and music. Her presentation covers this latter period of her life and focuses on specific vignettes where music has acted as a conduit for change and healing for people she has worked with and for herself personally as a cancer survivor.

Prof Elizabeth Eakin
University of Queensland

Elizabeth Eakin is Head of the Division of Disease Prevention and Control and Director of the Cancer Prevention Research Centre in the School of Public Health at the University of Queensland, Brisbane, Australia. For the past 12 years, she has been the recipient of research fellowship funding from the Australian National Health and Medical Research Council. She is a behavioural scientist with extensive experience in the conduct of randomised controlled trials of interventions to promote healthy lifestyles among cancer survivors, particularly targeting physical activity, healthy eating and modest weight loss. Her research program is focussed on evidence translation, and as such, she has built relationships with cancer control partners, including clinicians and state and federal government and non-government organisations across Australia. In her presentation, she will be discussing her most recent translational trial, Healthy Living after Cancer, involving collaboration with four Australian state-based Cancer Councils, with the emphasis on translating evidence for physical activity and weight control in cancer survivors into practice at the community level.

Kate Fennell
University of South Australia

Kate is a Research Fellow at the Sansom Institute for Health Research, University of South Australia. She has a Bachelor of Psychology with Honours, Masters of Psychology (Clinical), PhD and clinical experience working with people affected by cancer. Her research interests include understanding and addressing the psychosocial and tertiary prevention needs of rural cancer survivors, rural help-seeking behaviour and online and telephone-based supportive care interventions. During her PhD Kate developed a supportive care website for rural South Australians, www.countrycancersupport.com.au and in 2013 she was named the South Australian Young Achiever of the Year for this work.

Mr John Friedsam
CanTeen

John Friedsam is the General Manager of Divisions at Canteen Australia. John has specialised in psycho-oncology service provision and management for the past 14 years. He is passionate about developing and delivering evidenced based, sustainable supportive care, counselling and group work services to cancer patients and their families. John has also worked extensively in space of the impact of cancer on families, cancer communications and familial adjustment to cancer – most recently concentrating his work directly adolescents and young adults who are dealing with a cancer diagnosis, that of a family member, or are bereaved due to a cancer related death.

Prof Afaf Girgis
Ingham Institute for Applied Medical Research and UNSW

Professor Girgis is Director of the Psycho-oncology Research Group at the Ingham Institute for Applied Medical Research & UNSW in Sydney, Australia. With 25+ years of research experience, Prof Girgis' national and international standing in behavioural science and psycho-oncology was acknowledged in 2012 with the award of the Clinical Oncology Society of Australia (COSA) Inaugural Psycho-oncology Award and in 2015 she received the Lady Mary Fairfax Distinguished Researcher Award. She has 280+ publications, almost 8000 citations of her research and $46 Million in research funding. She has a strong commitment to translating research into clinical practice; and a demonstrated track record of effective engagement with service providers, end-users of research and the community, to ensure the relevance and acceptability of interventions aimed at improving cancer care and outcomes.

Kalinda Griffiths
University of Sydney and Menzies School of Health Research

Kalinda is a Yawuru woman and epidemiologist. She is the Wingara Mura Leadership Program Research Fellow at the Sydney Centre for Aboriginal and Torres Strait Islander Statistics at the University of Sydney and Honorary Fellow with Menzies School of Health Research. Her work includes addressing disparities between Indigenous and non-Indigenous people with cancer and understanding how to better measure health inequities. Kalinda has worked in Indigenous health research since 1997, with particular interest in data linkage and how descriptive epidemiology is translated to health policy and practice to close the gap in Indigenous health. She is located in Darwin and is also a cancer survivor.

Tony Hamdorf
Cancer Voices

Tony was first diagnosed with Stage IV bowel cancer in October 2008 and since then has adopted a holistic approach to dealing with the disease. By incorporating medical interventions with complimentary care including diet, exercise, mind training and a supplement program he has maintained himself in the best health possible. The journey that he has travelled has been very challenging at times and the changes to his life have been significant. These include the impact to family, friends, work, finances, diet and dealing with side effects of the disease while attempting to live a "normal life". Tony is also a member of Cancer Voices and believes that by sharing his experience with fellow cancer survivors, medical practitioners and care givers is very beneficial not only for them but also for himself.

Clinical Professor David Joske
Sir Charles Gairdner Hospital

Professor David Joske was Head of Haematology at Sir Charles Gairdner Hospital 1994 – 2012 and is now Medical Co-Director of the Medical Specialties Division there. His clinical and research interests include the treatment of lymphomas; palliative care in Haematology; and supportive care in cancer. He has held two NHMRC Grants, one examining models of palliative care in Haematology and the other his shared cancer care model. He launched the SolarisCare Foundation in September 2001, and is currently its Chairman and Chief Medical Officer. He is a UWA Clinical Professor of Medicine; has published over 65 peer-reviewed publications plus three book chapters and has presented a TED talk on "Re-humanizing Cancer Care". He is the WA Cancer & Palliative Care Network Clinical Lead for Survivorship and Director of the Charles Day Leukaemia & Lymphoma Tissue Bank. He was awarded the John Curtin Medal in 2005 and has been a finalist four times for Western Australian of the Year. He is the Ernst & Young 2016 Western Region Social Entrepreneur of the Year. He is an award-winning songwriter and plays guitar in a blues band.

Prof Bogda Koczwara
Flinders Centre for Innovation in Cancer
Professor Bogda Koczwara is a medical oncologist at the Flinders Centre for Innovation in Cancer in Adelaide and the National Breast Cancer Foundation Fellow. Her clinical interests revolve around management of breast cancer, survivorship care, psychooncology and supportive care and she has a particular interest in strengthening of the interface between specialist and primary care for cancer patients especially in rural Australia. Professor Koczwara leads the Survivorship Program at the Flinders Centre for Innovation in Cancer. She is the Lead in Survivorship for the South Australian Health and Medical Research Institute Comprehensive Cancer Consortium and she leads the development and implementation of the survivorship framework for cancer patients in South Australia. Professor Koczwara is the past President of the Clinical Oncology Society of Australia (COSA), the peak cancer professional organisation in Australia and the past president of the Medical Oncology Group of Australia (MOGA), the national professional organisation of medical oncologists. She is the initiator and the immediate past Chair the Australia Asia Pacific Clinical Oncology Research Development, a collaborative of international cancer organisations aimed at improving cancer research capacity in Australia and Asia Pacific. Professor Koczwara has been recognized as a Member of the Order of Australia in January 2015 for her services to oncology through clinical practice, education and research and through a range of professional organisations.

Prof David Roder
University South Australia
Since 2011 David Roder has been Chair of Cancer Epidemiology and Population Health at the University South Australia in collaboration with Cancer Council SA's Beat Cancer Project. He is also employed under contract by Cancer Australia, the NSW Cancer Institute, and Cancer Council SA. He has been a WHO consultant in Mongolia, Malaysia and Indonesia, and has worked under contract to the Malaysian, South Australian and New Zealand Government. He presently Chairs the National Cervical Cancer Quality Safety Monitoring Committee, the Australian Prostate Clinical Cancer Registry Steering Committee, the National Prostate Cancer Health Research Outcomes Unit, CanTeen Youth Cancer Service Data Advisory Panel, and Australian Commission on Safety and Quality in Health Care Interactive Atlas Committee. He sits on a range of other advisory, data set specification, accreditation and redevelopment committees. He has authored over 240 peer-reviewed research publications and is active in research both as a researcher and research reviewer for numerous international journals and research funding bodies and has reviewed research units in SA, WA, NSW, Qld, Victoria, Tasmania and nationally. David Roder's research interests are broad, but with a focus on cancer, health-services evaluation, safety and quality monitoring, and data-infrastructure development, and with an additional emphasis on data linkage. As Deputy Chair of the SA Government HREC, and member of the Population Health Research Network of Australia's Privacy Committee, he is interested in, and is optimising data use through data linkage within legal and ethical constraints.

John Stubbs
Survivor
Eighteen years ago John was diagnosed with Chronic Myeloid Leukaemia. Following a successful bone marrow transplant in 2001 he became a committed and passionate advocate for people affected by cancer. He holds degrees in Accounting and Arts and is a regular speaker at medical conferences in Australia and internationally about health and cancer policy, advocacy, clinical trials, research and related issues. John was awarded an Honorary Associate of the University of Sydney - School of Medicine in 2009 for work in the promotion of Clinical Trials in Australia and a Recognition Award from the Federal Department of Health in 2011 for – "long standing commitment to advancing the quality of radiation oncology services in this country". He currently holds four Board positions – Cancer Institute NSW, Medical Board of NSW Health Consumers NSW, NSW Illawarra and Shoalhaven Health district as well as a member of 16 Federal and State Government Health and Research Committees. John has contributed to over 40 research papers as an Investigator and Associate Investigator.

Dr Danielle Tindle
Queensland University of Technology
Danielle is a postdoctoral researcher at the Institute of Health and Biomedical Innovation, Queensland University of Technology (QUT). Her career focus in research and advocacy evolved from an early interest in international human rights and a desire to elevate under-represented voices in society. For over a decade, she has been working in the field of adolescent and young adult cancer. Her interests include the sociology of health and illness, the role of consumers in healthcare policy and practice, and the experiences of young people impacted by cancer. More recently, her interests have broadened to include the healthcare inequities experienced by people with rare or less common cancers and the financial toxicity of cancer. A diagnosis of lymphoma in her early twenties propelled Danielle into this field of work. Her more recent diagnosis of a rare cancer in 2015 again presented Danielle with new challenges in research and advocacy to shape much-needed policy reform. At the core of her work is a strong desire to represent marginalised groups in the healthcare system; voices that are often silenced or overlooked. As well as her PhD in young adult cancer

survivorship, completed at QUT in 2015, Danielle also holds a Masters of International Studies, a Bachelor of Arts majoring in Philosophy and a postgraduate diploma in Teenage and Young Adult Cancer Care.

Dr Lyndal Trevena
University of Sydney
Lyndal co-leads the Discipline of General Practice at the University of Sydney and has been a practising GP for almost thirty years. She currently runs specialised research translation clinics at the University of Sydney's academic health centres and provides pro bono care at the Asylum Seekers Centre in Newtown. She teaches primary health care within the international public health masters program and co-leads an NHMRC Centre for Research Excellence with international recognition for her research in shared decision-making. She has been a founding member of the Primary Care Cancer Clinical Trials Collaborative (PC4) and is also a cancer survivor herself.

Mrs Karen van Gorp
Melanoma Patients Australia SA Facilitator
Karen is a stage IV melanoma survivor who is now an advocate for and supporter of other melanoma patients. She also has 3 children and works part time in a policy role. Karen was diagnosed in 2011 with a Clark level III melanoma on her right shoulder blade and subsequently diagnosed in mid-2013 at stage IV. She was treated with Keytruda as part of a trial from October 2013 and is now clear of tumours. In gratitude for the success of her treatment Karen now represents melanoma patients in several forums and provides both group and one on one support to other melanoma patients.

Professor Janette Vardy
Concord Cancer Centre, University of Sydney
Prof Janette Vardy is a medical oncologist working as a clinician researcher at the Concord Cancer Centre, University of Sydney. After completing a Clinical Research Fellowship at the Princess Margaret Cancer Centre and a PhD in Clinical Epidemiology at the University of Toronto under the supervision of Dr Ian Tannock, she returned to Australia in 2007 and together with Dr Haryana Dhillon established the Survivorship Research Group (SuRG) at the University of Sydney. Her main areas of research are Psycho-Oncology, Quality of life and Survivorship, with a particular interest in cognitive function and physical activity in cancer survivors. In 2013 she established the Sydney Survivorship Centre at Concord Cancer Centre. In her spare time she enjoys playing the trumpet.

Program

Thursday 2 February 2017

Registration

7:30AM - 5:30PM *Panorama Room Foyer*

Official welcome & welcome to country

8:45AM - 9:00AM *Panorama Rooms 1,2&3*
Chairs: Bogda Koczwara & Phyllis Butow

Quality survivorship care: Policy to support best practice

9:00AM - 10:30AM *Panorama Rooms 1,2&3*

Chairs: Bogda Koczwara & Phyllis Butow

9:00 AM **Elizabeth Jane Maher**
Survivorship in the UK – making change happen *abs# 1*
9:20 AM **Catherine Alfano**
Survivorship in the USA – making change happen *abs# 2*
9:40 AM **Sanchia Aranda**
Survivorship in Australia– making change happen *abs# 3*
10:00 AM **David Copley**
Where are the Indigenous Cancer Survivors? *abs# 4*
10:20 AM **Discussion**

Morning tea & Poster viewing

10:30AM - 11:00AM
Session sponsored by: *Panorama Room Foyer*
abbvie

Implementing quality survivorship care

11:00AM - 12:30PM *Panorama Rooms 1,2&3*
Chairs: Janette Vardy and Julie Marker

11:00 AM **Amanda Piper (on behalf of Nicole Kinnane)**
How will cancer survivors use survivorship care plans (SCPs)? *abs# 5*
11:15 AM **Bogda Koczwara**
The gap between theory and practice; uptake and quality of care plans and treatment summaries across survivorship care pilot sites in South Australia *abs# 6*
11:30 AM **Lauren McClean**
Collaborating with Cancer Treatment Centres to deliver a cost-effective and sustainable model of program delivery for cancer survivors *abs# 7*
11:45 AM **Joanna E Fardell**
Childhood cancer survivor and physician reported barriers to delivering survivorship care *abs# 8*
12:00 PM **Gemma Skaczkowski**
Do experiences of care at the end of treatment influence the psychosocial wellbeing of Adolescents and Young Adults (AYAs) with cancer? *abs# 9*
12:15 PM **Georgina E Wiley**
A multi-site cancer survivorship clinical placement program for primary care practitioners (PCPs) *abs# 10*

Lunch & Poster viewing

12:30PM - 1:30PM
Session sponsored by: *Panorama Room Foyer*
abbvie

Survivorship and disparities

1:30PM - 2:30PM *Panorama Rooms 1,2&3*
Chairs: Afaf Girgis & David Copley
1:30 PM **David Roder**
Measuring and reporting cancer and cancer management disparities in Australia *abs# 11*
1:45 PM **Kalinda Griffiths**
Closing the gap for indigenous cancer survivors *abs# 12*
2:00 PM **Afaf Girgis**
Issues for cancer survivors of non-English speaking backgrounds *abs# 13*
2:15 PM **Kate Fennell**
Issues for regional and rural cancer survivors *abs# 14*

Supporting healthy living in the growing population of cancer survivors

2:30PM - 3:30PM *Panorama Rooms 1,2&3*
Chairs: Elizabeth Eakin & Chris Christensen

2:30 PM	**Catherine Alfano** Population-level Approaches to Supporting Healthy Living in the Growing Population of Cancer Survivors *abs# 15*
2:45 PM	**Elizabeth Eakin** Supporting healthy living in the growing population of cancer survivors - engaging policy and practice partners *abs# 16*
3:00 PM	**Lyndal Trevena** The role of general practice *abs# 17*
3:15 PM	**Panel Discussion**

Afternoon tea & Poster viewing

3:30PM - 4:00PM
Session sponsored by: *Panorama Room Foyer*
abbvie

Healing through the arts

4:00PM - 5:30PM *Panorama Rooms 1,2&3*
Chair: David Joske & Jennifer Donovan

4:00 PM	**David Joske** Healing and the Arts: Framing a Dialogue *abs# 18*
4:25 PM	**Elizabeth Jane Maher** Emotional rescue *abs# 19*
4:45 PM	**Jennifer Donovan** Surviving through music *abs# 20*
5:00 PM	**David Joske** Song-writing as therapy *abs# 21*
5:15 PM	**Jenny Donovan (keyboards), David Joske (guitar) & Janette Vardy (trumpet)** Trumpeting your success – musical performance

Welcome reception

5:30PM - 7:30PM *Riverbank Promenade*

Friday 3 February 2017

Ashleigh Moore Award Oration

9:00AM - 9:30AM *Panorama Rooms 1,2&3*

9:00 AM	**John Stubbs** Cancer statistics and the power of one

Measuring what matters

9:30AM - 10:30AM *Panorama Rooms 1,2&3*

Chairs: Nadia Corsini & Raymond Chan

9:30 AM	**Marion Eckert** Willingness of cancer survivors to complete patient reported outcomes (PRO) surveys: a pilot study at Flinders Centre for Innovation in Cancer (FCIC), South Australia *abs# 22*
9:45 AM	**Lynette Jeffreson and Cynthia Opie** Evaluation of the effectiveness of Supportive Care Screening in rural ambulatory cancer care at Echuca Regional Health *abs# 23*
10:00 AM	**Harold B. Stewart** ACME – A Patient Reported Experience Measure (PREM) for Aboriginal people with experience of cancer *abs# 24*
10:15 AM	**Eva Battaglini** Chemotherapy-induced peripheral neuropathy: Determining impacts on cancer survivors *abs# 25*

Morning tea & Poster viewing

10:30AM - 11:00AM
Session sponsored by: *Panorama Room Foyer*
abbvie

Survivorship when cancer cannot be cured

11:00AM - 12:30PM *Panorama Rooms 1,2&3*
Chairs: Fiona McRae

11:00 AM	**Bogda Koczwara** Internet support needs and preferences of women living with advanced breast cancer *abs# 26*

11:15 AM **David Wyld**
'How long is the piece of string?' – How patients negotiate the uncertainties of a Neuroendocrine tumour diagnosis *abs# 27*

11:30 AM **Katriona M Smith**
How confident would you be? An analogue study of interpersonal and situational factors influencing caregiver self-efficacy in the context of advanced cancer *abs# 28*

11:45am **Panel discussion with survivors and health professionals**
What is the impact of definition of survivorship on how we implement it?
Facilitator: Fiona McRae

Panellists:
Catherine Alfano
Tony Hamdorf
David Joske
Jane Maher
Karen Van Gorp

Lunch & Poster viewing

12:30PM - 1:30PM
Session sponsored by: *Panorama Room Foyer*
abbvie

What we do not talk about

1:30PM - 3:00PM *Panorama Rooms 1,2&3*
Chair: Haryana Dhillon & John Stubbs

1:30 PM **Haryana Dhillon**
Introduction – Who is "we"?

1:35 PM **Haryana Dhillon**
Let's talk about sex – in conversation with a Rekindle study participant *abs# 29*

1:50 PM **Antoinette Anazodo**
Fertility preservation *abs# 30*

2:05 PM **John Friedsam**
Family matters: How cancer impacts parents, partners, offspring, and siblings? *abs# 31*

2:20 PM **Bogda Koczwara**
The financial burden of cancer – an unspoken side effect of cancer *abs# 32*

2:50 PM **Discussion**

Afternoon tea & Poster viewing

3:00PM - 3:30PM
Session sponsored by: *Panorama Room Foyer*
abbvie

You are not alone

3:30PM - 5:00PM *Panorama Rooms 1,2&3*
Chair: Annie Miller & Dan Kent

3:30 PM **Monique Bareham and Ruth Klee**
Minding the Gap – Consumer led programmes can fill a much needed Cancer Related Lymphoedema management space *abs# 34*

3:45 PM **Fiona McRae**
Peer support volunteers with advanced cancer: meeting unique needs on the survivorship continuum *abs# 35*

4:00 PM **Courtney Oake**
Reflections on My Experience as a Survivor *abs# 36*

4:15 PM **Imerman Angels (video link to USA)**

4:35 PM **Panel discussion with survivors and health professionals**
How can we all support each other to make a lasting change?
Panellists:
Catherine Alfano
Monique Bareham
David Copley
Bogda Koczwara
Fiona McRae
Courtney Oake

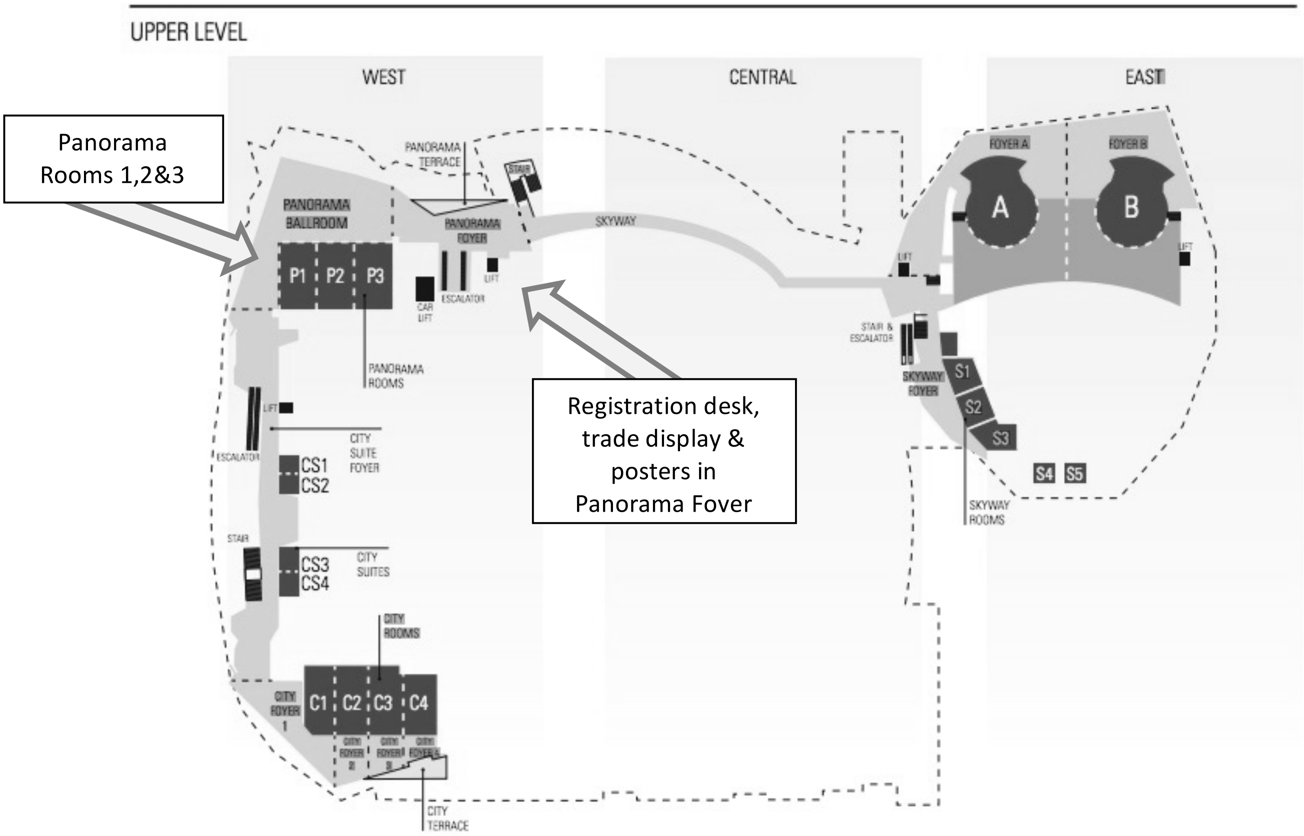
Closing remarks, conference reflections, next steps

5:00PM - 5:10PM *Panorama Rooms 1,2&3*
Bogda Koczwara

Delegate Information

Venue: Adelaide Convention Centre, Panarama Rooms 1,2&3

The multi-award winning Adelaide Convention Centre enjoys a global reputation for excellence and is consistently ranked among the world's top convention centres. The convention centre is located next to the Adelaide Railway Station and within walking distance of trams, accommodation and the CBD. If you have any questions during the meeting, don't hesitate to ask at reception or see ASN Events staff at the Conference registration desk.



Registration desk

The registration desk will be located in the Panorama Room Foyer and will be open from 7.30am to 5.00pm Thursday and 7.30am to 3.30pm Friday.

Session rooms

All sessions will be held in Panorama Rooms 1,2&3. Breaks and posters will be held in the Panorama Room Foyer. The welcome reception on Friday evening will be held on the Riverbank Promenade.

What is included in your full registration

- Access to all sessions
- Conference book
- Welcome reception (including dinner and beverages)
- Morning teas, afternoon teas and lunches
- Access to the conference app
- Conference satchel

Name tags

Delegates are required to wear their name tags to all sessions.

Social function

The welcome reception is being held on Thursday 2 February on the Riverbank Promenade at the Adelaide Convention Centre (Lower Level) from 5.30pm to 7.30pm. A BBQ dinner and beverages will be served.

Internet access at the conference

To gain access to the WIFI network go into your WIFI preferences on your personal device and search for the network "Survivorship" then when prompted for a password enter "adelaide".

Conference App

The official Survivorship web based 'App' will keep you organised during the meeting. The output is displayed in a simple and easy to read format on your phone, iPad, or even your computer. To get the 'App', please open the following link in your internet browser. You can save the page to your home screen; the conference logo will then appear as an icon on your home screen for you to open as an 'App'. You must *log in* each day to utilise all of the functions. Simply enter the same email & password you used to register. The web based 'App' will allow you to:

- View the full conference program
- View all abstracts for the conference
- View speaker bios and photos
- Save your favourite sessions and plan your day

http://survivorship-2017.m.asnevents.com.au

Mobile Phones

Please ensure your mobile is turned off or to silent during the sessions.

Instructions for oral presenters

Please load your presentation onto the computer in the room on the morning of the day you are presenting or in the break prior to your session commencing. The standard AV set up for all presentations will be data projection using MS PowerPoint. As per instructions already supplied, you will need to have your talk supplied on a USB thumb drive. If you wish to use your Mac please ensure you bring the appropriate projector converter cables. ASN staff members will be onsite to assist.

Instructions for poster presenters

Poster viewings will be held during all three breaks on Thursday 2 February and Friday 3 February 2017:

Thursday 2 February 2017
Morning tea: 10:30am – 11am
Lunch: 12:30pm – 1:30pm
Afternoon tea: 3:30pm – 4:00pm
Friday 3 February 2017
Morning tea: 10:30am – 11am
Lunch: 12:30pm – 1:30pm
Afternoon tea: 3:00pm – 3:30pm

It is required that you stand by your poster during all breaks Thursday 2 February, and optional Friday 3 February. You can mount your poster upon arrival at the conference. There will be Velcro available on the poster boards provided. Please ensure your poster has been taken down by afternoon tea on Friday 3 February. Any posters not collected will be discarded.

Insurance

The hosts and organisers are not responsible for personal accidents, any travel costs, or the loss of private property and will not be liable for any claims. Delegates requiring insurance should make their own arrangements.

Disclaimer

The hosts and organisers are not responsible for, or represented by, the opinions expressed by the participants in either the sessions or their written abstracts.

Smoking

Smoking is not permitted in the venue.

Local Information

Once considered a sleepy city, Adelaide is undergoing a rapid transformation with a burgeoning small-bar scene, world-class art and music, and a festival calendar to rival that of any other Australian city. Discover its laneway secrets, take in the stunning flora at the Adelaide Botanic Gardens, and find delicious treats around every bend.

Drink and dine in laneway bars: In the city centre, Adelaide’s laneways and side streets are being transformed with hidden bars and eateries. Along Peel Street enjoy a whisky at Clever Little Tailor or espresso martini at La Moka. Hains & Co is a sailor-themed bar tucked down Gilbert Place, specialising in gin and rum. One of Adelaide’s hottest bars, Proof, can be found on Anster Street, which pairs classic cocktails with tasty share plates and gourmet toasted sandwiches. Underground bar Bank Street Social is the go-to for local craft beer and Australian spirits, while La Buvette Drinkery serves French apéritifs with a side of escargot. Get your caffeine hit at Coffee Branch on Leigh Street, and dine on playful, modern Australian cuisine at Peel St.

Stroll along North Terrace: Visit Adelaide’s tree-lined boulevard, North Terrace, home to the city’s most important cultural institutions. Housed in one of Adelaide’s most beautiful buildings, the Art Gallery of South Australia features a collection of more than 38,000 works spanning Australian, European, North American and Asian art. Delve into Australia’s natural and cultural heritage at the neighbouring South Australian Museum. From here it’s a 20 minute stroll to the Botanic Gardens, where you can wander among thousands of species of roses, and see three impressive glasshouses including the exquisite 1877-built Palm House. If you’re travelling with kids don’t miss the Adelaide Zoo, home to native Australian wildlife including koalas, Australia sea lions and kangaroos.

Relax on the beach: When the mercury rises, head to one of Adelaide’s many popular ocean beaches. Catch the 25 minute tram from Rundle Mall to Glenelg, a bustling beachside neighbourhood with heritage hotels, alfresco cafés and a white sandy beach. For the ultimate retro beach experience, drive 14 kilometres (9 miles) south of Adelaide to Semaphore, where you can walk along the esplanade, tuck into fish and chips or swim in its sheltered waters. If you’re looking to hit the surf, both novices and experienced surfers are catered for on the Fleurieu Peninsula, a 45 minute drive south of Adelaide.

Sample fresh produce at Adelaide Central Market: Savour South Australia’s rich bounty of produce – farm-fresh fruit and vegetables, artisan cheeses, smoked meats and seafood – at Adelaide Central Market. For more than 140 years, the undercover market has been the epicentre for Adelaide’s food scene. Start with coffee at Fair Espresso and freshly baked pastries at Dough. Sample the local cheeses at Say Cheese and hard-to-find international cheese at The Smelly Cheese Shop. Drop by Island Pure, which brings together more than 25 producers from Kangaroo Island, and stocks small-batch gin, flavoured oils, honey and sticky figs. To discover the best of the market, join Mark Gleeson’s early morning walking tour, during which you’ll enjoy generous tastings and meet the people behind the stalls.

Go shopping: Explore Adelaide’s East End at Rundle Street. Originally home to Adelaide’s central market, the area is undergoing a retail renaissance with fashion boutiques and specialty stores attracting the city’s style set. Find major department stores at Rundle Mall, shop for homewares along Norwood Parade and visit nearby Magill Road for art and antiques.

Head for the hills: Spend a day or two exploring the Adelaide Hills, one of Australia’s top cool-climate wine regions. Drop into some of the region’s 60 wineries such as Hahndorf Hill, which is pioneering the Austrian grape varieties, or Bird in Hand, renowned for its award-winning Shiraz. Afterwards enjoy a leisurely lunch at The Lane Vineyard, dining on dishes such as crisp pork belly and Hereford 40-plus days dry aged striploin, at its hilltop dining room. If you’re visiting on the weekend, don’t miss the Adelaide Hills Farmers’ Market for a taste of fresh, seasonal and local produce. Stay overnight in quaint country cottages or drive an easy 30 minutes back to central Adelaide.

Poster Listing

Natalie Bradford
Interventions for health and well-being in adolescents and young adults after cancer: a systematic review *abs# 40*

Natalie Bradford
Fertility issues in young people after cancer: what do I need to know? *abs# 41*

Natalie Bradford
Establishing an integrated state-wide adolescent and young adult cancer service *abs# 42*

Raymond J Chan
Patient-clinician discussions about fertility in the adolescent and young adult cancer population: A multi-centre retrospective study *abs# 43*

Robin D Curwen-Walker
The Bridge of Support - A collaborative Approach to a Peer Support Program *abs# 44*

Carolyn Der Vartanian
A new model supporting best practice follow-up care for early breast cancer in Australia: shared follow-up care for early breast cancer *abs# 45*

Haryana M Dhillon
Exercise during cancer treatment: A pilot survey of what Australian Cancer Health Professionals think *abs# 46*

Jo Anne R Dumalaon
Fear of cancer recurrence and psychological well-beingin women with breast cancer: The role of causal cancerattributions and optimism *abs# 47*

Joanna E Fardell
Transition of childhood cancer survivors to adult survivorship care: survivor preferences, and barriers to care *abs# 48*

Kathy Flitcroft
Documenting health service inequities and identifying potential criteria for addressing them: A case study of breast reconstruction in Australia *abs# 49*

Corinna Freytag
The relationship between resilience, distress and quality of life in cancer patients and survivors *abs# 50*

Jessica Fullerton
The Victorian Paediatric Long Term Follow-up Program for survivors of childhood cancer - Model of care *abs# 51*

Spiridoula Galetakis
Measuring what matters: An evaluation and outcomes framework for survivorship care programs *abs# 52*

Paul Glare
Returning to work was important in a survey of American palliative care patients *abs# 53*

Paul Glare
Severe pain, disability, psychological distress and maladaptive coping are common in cancer patients attending Australian pain clinics *abs# 54*

Michael C Hartland
Ability to adhere to exercise guidelines during stereotactic ablative body radiation therapy for metastasis of renal cell carcinoma in the superior lobe of the left lung: a case study report *abs# 55*

Genevieve Johnston
Developing a sustainable model of care for cancer survivors *abs# 56*

Michelle Judd
Survivorship in a Regional Setting *abs# 57*

Richard Cohn
Long term outcomes and risk factors for chemotherapy induced peripheral neuropathy in childhood cancer survivors *abs# 58*

Dan Kent
"Engage Community Forums" An initiative developed and driven by GI Cancer survivors and carers *abs# 59*

Ruth V Klee
Living an adventurous life with Lymphoedema: One patient's journey to acceptance and Management *abs# 60*

Tricia LaBella
The self-coach BREATHE approach to optimise quality of life after cancer *abs# 61*

Eleanor Law
Life after cancer treatment - a peer support group pilot study *abs# 62*

Heidi McAlpine
Improving brain tumour care online *abs# 63*

Lauren McClean
Enriching Survivorship *abs# 64*

Jill Mills
Webinars providing education and empowerment for cancer survivors and health professionals *abs# 65*

David Mizrahi
Physical activity in survivors of childhood cancer: results from a long-term follow-up study, systematic review and meta-analysis *abs# 66*

Caroline Nehill
Principles of Cancer Survivorship – guiding a national approach to policy and health services planning *abs# 67*

Huah Shin Ng
Development of comorbidities in hormone-dependent breast cancer survivors treated with endocrine therapy: an Australian population-based analysis *abs# 68*

Antionette Anazodo
A patient survey to develop follow up care for 15 -25 year olds with a cancer diagnosis, 1-5 years after the completion of cancer treatment. 'Will establishing a multidisiciplinary psychosocial clinic improve outcomes, provision and coordination of this age group?' *abs# 69*

Peter K O'Shaughnessy
Love, Faith and Hope - A secondary analysis of prostate cancer survivors and their partners *abs# 70*

Neil B Piller
Clinical Innovations: Lymphoedema management *abs# 71*

Amanda Piper
Promoting the role of primary care in cancer survivorship *abs# 72*

Meron E Pitcher
Engagement of general practice in cancer survivorship *abs# 73*

Kathryn Rorke
Does multidisciplinary outpatient oncology rehabilitation meet the needs of cancer survivors? A retrospective study *abs# 74*

Josie Samers
Five years of GP shared care for cancer survivors with complex needs: what have we learned? *abs# 75*

Meron Pitcher
Key strategies and learning in the development, sustainability & transferability of a model of survivorship care *abs# 76*

Camille E Short
Breast cancer survivors' long-term goals for participating in an online physical activity program. Lessons learned in the iMove more for life RCT *abs# 77*

Joanna E Fardell
Models of follow-up care in Australia and New Zealand: challenges to implementing optimal survivorship care in paediatric cancer *abs# 78*

Maryanne Skarparis
Fit to Thrive: Outcomes of a specialised exercise program to support patients with a haematological malignancy *abs# 79*

Jennifer Soon
A systematic review of late effects in survivors of stage I seminoma *abs# 80*

Denise Stewart
Low referral of breast cancer survivors to rehabilitation and wellness services: A project to improve service provider networking *abs# 81*

Fiona Tansley
Testing the effectiveness of online training delivery targeted at improving healthy living knowledge, skills and confidence of breast cancer survivors *abs# 82*

Karen M Taylor
Development of a Survivorship Care Plan and Treatment Summary for Lymphoma Survivors *abs# 83*

Haryana M Dhillon
Facilitators and barriers to participation in a weight management study for cancer survivors: A qualitative exploration *abs# 84*

Janette L Vardy
Physical and psychological health status of cancer survivors following primary adjuvant treatment *abs# 85*

Adam K Walker
We need to be measuring inflammatory biomarkers: A preclinical model of breast cancer-induced cognitive impairment points to neuroinflammation as the mechanism *abs# 86*

Georgina E Wiley
Development of written resources with and for culturally and linguistically diverse cancer survivors in Australia: lessons learnt *abs# 87*

info@pc4tg.com.au | www.pc4tg.com.au

CANCER RESEARCH IN PRIMARY CARE
PRIMARY CARE COLLABORATIVE CANCER CLINICAL TRIALS GROUP

Fostering collaboration in primary care to:

- Build research capacity
- Develop pre-trial research leading to multi-site, large scale studies
- Fill the research gaps in oncology in primary care
- Improve health outcomes and care for cancer patients

Abstracts

1

Survivorship in the UK – making change happen

Elizabeth Jane Maher[1]

1. Macmillan Cancer Support, London, United Kingdom

There are increasing numbers of people living with and beyond cancer. In high income countries more than half of those diagnosed with cancer will live more than 10 years, however, surviving cancer does not necessarily mean living well. An estimated one in four will be dealing with treatment related consequences and living with active "chronic cancer", in addition, two thirds of those with cancer will have at least one other condition e.g. hypertension, chronic heart disease, mental health issues or diabetes. Since 2007 there have been a range of national survivorship initiatives across the countries of the United Kingdom together with testing of initiatives, including risk stratified pathways of follow up care, a recovery package (holistic needs assessment, treatment summary, care plan and primary care review) after completion of initial cancer treatment. There have been national patient experience and quality of life surveys leading to the development of metrics to be integrated into routine data collection and interventions to support work, physical exercise and manage severe treatment related consequences. This work has involved collaborative working between cancer registries, charities, Royal Colleges and private sector management consultancies as well as National Health Service bodies. Some of the successes and remaining challenges will be discussed.

2

Survivorship in the USA – making change happen

Catherine Alfano[1]

1. American Cancer Society, Washington, DC, United States

Between 20-92% of patients treated for cancer develop toxicities that often go unaddressed, limiting their functioning, health, quality of life, and ability to work. To optimize patient wellness, we must prevent these conditions where possible or prescribe timely therapies that reduce impairment and prevent disability when impairments cannot be eliminated. This involves building a better model of care where toxicity risk and assessment begins at the time of cancer diagnosis and continue through and beyond cancer treatment. In this model, physical impairments and psychosocial symptoms are assessed and treated and exercise and nutrition interventions are provided to optimize functioning, health, and quality of life. To implement this vision, the United States is working on simultaneous strategies to improve oncology and survivorship care. Efforts include implementing evidence-based changes in healthcare delivery, patient education and empowerment, provider training, and policy reform, and informing new research initiatives to fill emerging gap areas.

3

Survivorship in Australia– making change happen

Sanchia Aranda[1]

1. Cancer Council Australia, Sydney, NSW, Australia

Cancer Council estimates that there are over 1.1 million Australians living with or following a diagnosis of cancer with Australia having amongst the best cancer outcomes in the world. However, many within this growing cohort of survivors live with ongoing physical, emotional, occupational, social and economic sequalae of cancer and its treatment. How our health and social systems can best respond to these needs will be the focus of this presentation.

Starting with the Australian policy landscape the presentation will examine Government and non-Government responses to the core components of the cancer survivorship experience. It will explore survivorship challenges including variations in access to quality survival, regulatory and funding issues in delivering quality survivorship and the need for system redesign to address survivorship care. successfully deliver best care for survivors now and into the future. The presentation will cover a range of recommended reforms of our system to successfully deliver best care for survivors now and into the future.

4

Where are the Indigenous Cancer Survivors?

David Copley[1]

1. Pangula Mannamurna Aboriginal Corporation, Mount Gambier, SOUTH AUSTRALIA, Australia

Cancer rates amongst Aboriginal and Torres Strait Islander populations are lower than that of Non-Indigenous Australians, however our mortality rate is higher than non-Indigenous Australians, particular amongst Aboriginal and Torres Strait Islander men.

Why is the Indigenous survival rate so poor?

Why is it so hard to identify these survivors and then encourage them to speak about this major killer of Aboriginal and Torres Strait Islander people?

There are a number of documented reasons why our survival rate and data is below that of non-Indigenous Australian. Firstly, Indigenous people are significantly more likely to have cancers that have a poor prognosis, are usually diagnosed with cancer at a later stage, are less likely to receive adequate treatment, and are more likely to die from cancers than other Australians (1).

Secondly reliable national data on the diagnosis of cancer for Indigenous Australians are not available. All state and territory cancer registries collect information on Indigenous status; however, in some jurisdictions the quality of Indigenous status data is insufficient for analyses. Information in the ACD on Indigenous status is considered to be of sufficient completeness for reporting for New South Wales, Queensland, Western Australia and the Northern Territory. Data for these four jurisdictions were used to examine the incidence of cancer by Indigenous status (2).

In this presentation we will briefly examine:

What are the significant barriers to the early diagnosis of two major types of cancer (that have high mortality rates amongst Indigenous Australians).

Why Aboriginal and Torres Strait Islander people are still uncomfortable talking about a disease that takes so many of their communities.

1. (1), (2) Cancer Australia.

5

How will cancer survivors use survivorship care plans (SCPs)?

Nicole Kinnane[1], **Amanda Piper**

[1], **Michael Jefford**[2, 3, 1]

1. Australian Cancer Survivorship Centre, A Richard Pratt Legacy, Peter MacCallum Cancer Centre, Melbourne, Victoria, Australia

2. Department of Cancer Experiences Research, Peter MacCallum Cancer Centre, Melbourne, Victoria, Australia

3. Sir Peter MacCallum Department of Oncology, The University of Melbourne, Melbourne, Victoria, Australia

Aims

SCPs have been internationally endorsed as an important tool to support enhanced post-treatment survivorship care. To support broad implementation of SCPs we investigated survivors' preferences regarding SCPs. The aims of the study were to determine survivors' preferences regarding the most valued information elements of a SCP and preferred delivery format. We also sought to determine intended use of a SCP and whether there were groups who felt they did not need a SCP.

Methods

The study was conducted at a single site. Eligible patients from 10 clinical services generally up to 12 months following end of treatment, were approached. A purpose designed survey assessed survivors' intended use of a SCP and preferences regarding format and content. Intended minimum sample size was 200.

RESULTS:

230 surveys were returned (RR 68%). 56% had completed treatment within 6 months, with 10% receiving ongoing treatments. Most (82%) had not received a SCP. 98% desired further information. Most common information requested was: 'a list of symptoms to watch out for and report' (76%), 'summary of treatment received' (70%), 'plan for follow-up appointments' (70%), and 'things I can do to look after myself' (67%). Most common reasons for wanting a SCP included: 'a record of cancer treatment' (63%), 'a reminder of things to do to look after myself' (57%) and 'to help me understand my cancer experience' (56%). 52% would share the information with their GP. 91% indicated a preference for paper-based resources. Both brief (36%) and detailed versions (42%) were supported. 55% preferred delivery during a face-to-face discussion with a health professional.

CONCLUSION:

While similar to international findings, results suggest alternate ways of providing information survivors desire. Most desired elements have been defined. Flexible approaches to SCP interventions are warranted. Impressing the value of sharing SCPs with GPs is recommended.

6

The gap between theory and practice; uptake and quality of care plans and treatment summaries across survivorship care pilot sites in South Australia

Bogda Koczwara[1], **Chantelle Hislop**[2], **Kate Cameron**[3], **Dagmara Poprawski**[3], **Nadia Corsini**[4], **Michael Osborn**[3], **Marion Eckert**[5], **Kate Turpin**[3], **Taryn Bessen**[3], **Michael Fitzgerald**[6], **Tracey Doherty**[2]

1. Flinders Centre for Innovation in Cancer, Bedford Park, SA, Australia

2. South Australian Cancer Service, Adelaide, SA, Australia

3. Central Adelaide Local Health Service, Adelaide, SA, Australia

4. The Cancer Council of South Australia, Adelaide, SA, Australia

5. University of South Australia, Adelaide, Australia

6. Southern Adelaide Health Service, Bedford Park, SA, Australia

Aims: To assess the uptake and quality of survivorship care plans (SCPs) and treatment summaries (TSs), and providers and survivors' perception of their utility.

Methods: As part of the development of the South Australian state-wide survivorship care framework, health providers delivering cancer care were invited to take part in an intervention pilot consisting of a nurse-led survivorship consultation and development of SCPs and TSs. Participants were supported by standardized tools, templates, and access to a professional network. Clinicians were encouraged to adapt the intervention into their existing practice. Demographic characteristics of survivors and process measures were collected. Outcomes included number of SCPs/TSs developed, completeness of information and quality of recommendations. Qualitative and quantitative feedback was sought from survivors and providers.

Results: Four teams comprising a nurse and a medical oncologist nominated to undertake a three-month pilot. 43 plans were developed (range 0-34). Median age of survivors was 59 (32-80), 36 (84%) were women and 32 (74%) had a breast cancer diagnosis. The average time required to prepare TS and SCP was 154 minutes (120-240). TSs had high level of completeness. The median number of issues identified in SCPs was 5.9 (3 - 11). All SCPs included cancer surveillance, only 20 (47%) included lifestyle recommendations. The quality of strategies was ranked low-moderate. Feedback from providers and survivors is currently being analysed and will be reported on at the time of presentation.

Conclusions: This work demonstrates the implementation gap between the theory and practice of survivorship care with high variation in uptake and quality of the intervention across four sites. While content accuracy was high, the quality of recommendations varied, which may reflect a training need. Ongoing trialing and re-evaluation of process and outcomes are required to refine the intervention to ensure high quality survivorship care.

7

Collaborating with Cancer Treatment Centres to deliver a cost-effective and sustainable model of program delivery for cancer survivors

Lauren McClean[1], **Jill Mills**[1], **Annie Miller**[1]

1. Cancer Council NSW, Kings Cross, NSW, Australia

Background:

Cancer survivors may experience complex health needs including chronic health conditions, some of which are preventable by adopting a healthy lifestyle. The ENRICH (Exercise and Nutrition Routine Improving Cancer Health) program was developed for cancer survivors, their partners, family and carers. ENRICH is evidenced-based, integrating health behaviour change models, utilising chronic disease self-management tools and social cognitive theory. Key principles include skill development, personal monitoring, goal setting and problem solving.

Aim:

To deliver the ENRICH program in a cost effective and sustainable manner through collaboration with Cancer Treatment Centres (CTC) and Health Professionals.

Methods:

Collaboration with CTC's to deliver the ENRICH program realises mutual benefits of;

- Cancer Council NSW (CCNSW) provides a comprehensively evaluated, replicable program
- CCNSW provides program resources and administration support
- CTC Health Professionals refer participants
- CTC provides venue and on-staff facilitators (Dietitian and Exercise Physiologist)

Results:

Since collaborating with CTC's in August 2013, 43 ENRICH programs have been delivered reaching 595 participants. 16 programs were delivered in CTC's costing$37 per head compared with 27 externally funded programs costing $190 per head. Collaboration with CTC's resulted in an 80% reduction in program costs.

Conclusions:

Collaboration with CTC's provides a cost-effective and sustainable model of program delivery for healthy lifestyle interventions.

Implications:

Collaboration with CTC's provides the opportunity to improve access for cancer survivors across NSW to the ENRICH program. Increasing knowledge regarding nutrition and exercise may result in reduced comorbidities and chronic health conditions in cancer survivors. Further investigation is required to assess if this collaborative approach is achievable in regional and remote areas of NSW and if Health Professional referrals has an impact on attendance rates and long-term behaviour change of cancer survivors.

8

Childhood cancer survivor and physician reported barriers to delivering survivorship care

Christina Signorelli[1], **Claire E Wakefield**[1], **Joanna E Fardell**[1], **Tali Foreman**[1], **Rebecca Hill**[1], **Jordana K McLoone**[1], **Richard J Cohn**[1]

1. Sydney Children's Hospital; UNSW Australia, Randwick, NSW, Australia

Aims: Many survivors are disengaged from essential, lifelong follow-up care following treatment for cancer as a child. Innovative models of follow-up care are therefore required to manage the increasing number of childhood cancer survivors (CCS). CCSs' preferences, and GPs' confidence in delivering survivorship care is underexplored.

Methods: *Stage 1:* CCS and parents (of survivors <16 years) were surveyed on their survivorship care preferences. *Stage 2:* Survivors' nominated their GP for an interview regarding their role and confidence in providing childhood cancer survivorship care. Analysis was performed using SPSS22.0 and NVivo11.

Results: *Stage 1:* 610 surveys were returned (403 CCS, mean age: 26.8years; and 207 parents, child mean age: 12.4years). Sixty-five percent of CCS reported having a regular GP. GP-led follow-up care was the least preferred choice, with significantly fewer parents nominated GPs as their first choice (2% vs 12% survivors $\chi2=32.183$, $p<0.001$). Parents were less willing to visit a GP for their child's survivorship care (39% vs 65% of survivors, $\chi2=24.097$, $p<0.001$). However, 22% of survivors reported not attending a long term follow-up clinic as they felt their GP was best placed to meet their needs (vs 5% of parents, $\chi2=20.457$, $p<0.001$). *Stage 2:* Only 16% of GPs (n=50) reported receiving a treatment summary or Survivorship Care Plan for their patient. Fifty-percent of GPs were confident in providing survivorship care to pediatric survivors, however 92% had unmet information needs particularly in understanding CCS' unique health needs.

Conclusions: GPs are willing to provide survivorship care to paediatric survivors, and are well placed to provide holistic care. Increased training and liaison between tertiary services and primary care may improve the confidence of survivors and GPs, therefore enhancing the quality of GP-led care.

9

Do experiences of care at the end of treatment influence the psychosocial wellbeing of Adolescents and Young Adults (AYAs) with cancer?

Vicki White[1], **Gemma Skaczkowski**[1], **Helen Bibby**[1], **Antoinette Anazodo**[2], **Kate Thompson**[3], **Lisa Orme**[3], **Rachel Conyers**[4], **Wayne Nicholls**[5], **Ross Pinkerton**[5]

1. Cancer Council Victoria, Melbourne, VIC, Australia
2. Sydney Children's Hospital , Sydney, NSW, Australia
3. Peter MacCallum Cancer Centre , Melbourne, Victoria, Australia
4. Royal Children's Hospital , Melbourne, Victoria, Australia
5. Children's Health Queensland , Brisbane, Queensland, Austraila

Aim: This study examined the psychosocial impact of experiences of care at the end-of-treatment for Adolescents and Young Adults (AYAs) with cancer. **Methods:** A cross-sectional survey was conducted with 209 AYAs, aged 15-24 years at diagnosis, of which 162 (77.5%) had finished cancer treatment. The survey response rate was 29%. Patients were recruited through population-based cancer registries in Victoria and New South Wales, Australia. Questions assessed experiences (including the provision of information and support) at treatment end and AYA's quality of life. **Results:** Participants were on average 9 months post-diagnosis (range 3-24 months) and had received surgery (76.5%), chemotherapy (56.2%) and/or radiotherapy (30.2%). At treatment end, a minority reported definitely being given a follow-up care plan (27%), a summary of their care (22%), information on how to manage ongoing side-effects (24%) or new symptoms to look for (32%). Only 21% reported being offered help returning to daily life and 19% reported being told about the emotions young people might face after finishing treatment. A scale constructed from these items indicated that more supportive end-of-treatment experiences were linked with better functional (B[95%CI]=5.45[2.37-8.52], *p*=.001), emotional (B[95%CI]=2.40[.24-4.56], *p*=.030) and social well-being (B[95%CI]=5.46[2.79-8.13], *p*<.001). The 39% of AYAs referred to emotional support services displayed better emotional (B[95%CI]=2.52[.46-4.58], *p*=.017) and social well-being (B[95%CI]=2.41 [.01-4.81], *p*=.049) than those not referred. Having follow-up tests and appointments coordinated by the health service to reduce hospital visits definitely occurred for 45% of patients and was associated with higher functional (B[95%CI]=2.10[.05-4.14], *p*=.044) and social (B[95%CI]=1.91[.11-3.71], *p*=.038) well-being. **Conclusions:** Results demonstrate the need for end-of-treatment support and information provision to be more routinely provided to AYAs with cancer. Supportive experiences at the end of treatment were positively associated with the psychosocial well-being of AYAs as they enter the survivorship phase.

10

A multi-site cancer survivorship clinical placement program for primary care practitioners (PCPs)

Georgina E Wiley[1, 2], **Amanda Piper**[1, 2], **Judy Evans**[1, 3], **Linda Nolte**[4], **Allison Drowdowsky**[5], **Liz Simkiss**[6], **Kathryn Whitfield**[6], **Julie Cairns**[4], **Giovanna Raco**[4], **Bruce Mann**[7], **Kerry Shanahan**[7], **Meron Pitcher**[8], **Bianca Bell**[8], **Michael Jefford**[2]

1. Peter MacCallum Cancer Centre, Melbourne, VICTORIA, Australia

2. Australian Cancer Survivorship Centre - A Richard Pratt Legacy, Peter MacCallum Cancer Centre , Melbourne, Victoria, 3000

3. OnTrac, Peter MacCallum Cancer Centre, Melbourne, Victoria, Australia

4. Austin Health, Melbourne, Victoria, Australia

5. Department of Cancer Experience Research, Peter MacCallum Cancer Centre, Melbourne, Victoria, Australia

6. Department of Health and Human Services, Melbourne, Victoria, Australia

7. Royal Melbourne Hospital, Melbourne, Victoria, Australia

8. Western Health, Melbourne, Victoria, Australia

Aims: Following a successful pilot, a survivorship placement program for PCPs (general practitioners (GPs) and general practice nurses (GPN)) was refined and extended to additional sites. The program aimed to facilitate collaborative learning, with an emphasis on the post treatment phase. Objectives were to improve clinical knowledge of the health needs of survivors and enhance confidence with shared care.

Methods: Four cancer centres participated. Each received an implementation toolkit and videos, developed to promote the role of PCPs in survivorship care. PCPs received pre-placement materials and attended multidisciplinary meetings and specialist clinics for 10 hours. PCPs and hospital-based specialists completed pre and post-placement surveys, assessing perceptions of the program, perceived barriers to shared care, perceived knowledge regarding survivorship issues (9 items), confidence managing survivorship issues (8 items) and with shared care (1).

Results: Forty-seven PCPs (32 GPs, 15 GPN) completed placements and pre and post-placement surveys. Median scores for all confidence items and 8 of 9 knowledge items increased; 1 remained the same. Matching of pre and post responses assessed individual changes. Across the 9 knowledge items, 57-86% of PCPs reported an increase; for the 9 confidence items, 68-89% reported improvement (no decreases). Data from specialists is currently available from one site; 16 specialists completed the pre- and 14 (88%) the post-survey. The majority of median knowledge and confidence scores were high and remained unchanged. Specialists (n = 14, 88%) and PCPs (n = 37, 76%) identified the biggest barrier to shared care as 'lack of systems to support transition of care.' All PCPs and specialists agreed/strongly agreed the 'program was relevant to my clinical practice.'

Conclusions: The program enhanced PCP's knowledge and confidence regarding survivorship care, was highly regarded and identified perceived barriers to shared care.

11

Measuring and reporting cancer and cancer management disparities in Australia

David Roder[1]

1. University of South Australia Centre for Population Health Research, Adelaide

A strategy for linking data extracts from cancer registry, pathology, hospital inpatient, radiotherapy-centre, health-insurance, screening and vaccination databases is outlined that is consistent with Cancer Australia's National Cancer Data Strategy. Non-identifiable data extracted, linked and accessed remotely for analysis using established privacy-protecting protocols, have a crucial role for monitoring cancer control activity in Australia and survival outcomes, including effects of primary prevention, screening and treatment services through to end-of-life care. Links to large population cohort data bases that incorporate risk behaviour, environmental exposure and other self-reported data are important. Linked bio-marker data can support research into the value of new markers of cancer risk and treatment effectiveness. Clinical cancer registries, where they exist, enable more detailed customized data to be used to check the fit-for-purpose validity of administrative data for system-wide monitoring. Prototypes of linked databases of this type exist at State and Territorial level, and their usefulness has been demonstrated in multiple studies for investigating trends in stage, other prognostic indicators, co-morbidity, patterns of care, survival outcomes, and side-effects of care, including late effects. Exploratory work is underway to determine the best means of collecting recurrence and progression data. Apart from providing an evidence base for population-wide and all-of-system cancer service planning, monitoring and evaluation, the data can be used for health-services and population health research, including investigations of the intermediate and longer term effects of new cancer drugs. Population-based survivorship data are lacking in Australia and are needed to for targeting and evaluating support services, evaluating the cost-utility of new cancer therapies and models of care, and for burden-of-disease studies. Means of obtaining these data population-wide, and including them in national linked cancer data, are discussed and recommendations made for including them in routine cancer monitoring.

12

Closing the gap for indigenous cancer survivors

Kalinda Griffiths[1]

1. The University of Sydney, LIDCOMBE, NSW, Australia

The evidence in better estimating and understanding the impact of cancer affecting Indigenous people has been developing progressively over the past ten years. While rates of cancer survival in Australia rank as one of the best in the world, there are known disparities in the incidence and outcomes for Indigenous people with cancer. To bridge the gap in disparities, improving the survivorship of Indigenous people involves the consideration of modifiable factors that are relevant to their wellbeing and their quality of life. The first step in addressing disparities in cancer survivorship in the Indigenous setting involves understanding what survivorship means. This requires the identification of factors and domains that wellbeing and quality of life will measure in order to better understand survivorship. It is acknowledged that Indigenous definitions of health encompass the physical, spiritual and emotional facets of the individual, family and the community. Therefore, it is expected that those factors contributing to quality of life and well-being for Indigenous people who have or have survived cancer will cover a range of topics including but not limited to connection to land, family, spirituality, physical, emotional, and psychological functioning, and social and community roles. To close the gap for Indigenous cancer survivors, there is a need for culturally-appropriate survivorship care.

13

Issues for cancer survivors of non-English speaking backgrounds

Afaf Girgis[1]

1. Ingham Institute for Applied Medical Research, UNSW, Liverpool, NSW, Australia

Australia is one of the most culturally and linguistically diverse countries in the world. The Cancer Council NSW reported that a quarter of cancers were diagnosed among migrants, which is proportional to their representation in the population. However international evidence suggests that ethnic minorities have higher cancer incidence, are diagnosed with later stage cancers, and have poorer outcomes than their Caucasian peers, and that the recent improvements in cancer survival in Australia are not being mirrored amongst the country's migrant population.

Approximately a third of cancer patients experience high levels of physical or psychological distress and the evidence is compelling that much psychosocial morbidity experienced by all cancer patients is not detected by health care providers and therefore remains untreated. Australian data indicate this is even more pronounced for CALD patients, with CALD cancer patients being shown to experience significantly lower quality of life and a higher incidence of clinical depression compared to their English-speaking counterparts. Australian CALD patients report more side effects in comparison to English-speaking patients, are less satisfied with their cancer care and have unmet needs relating to emotional support and information. CALD patients also face significant challenges regarding communication with their health care team and a lack of culturally sensitive resources, which contributed to a sense of isolation and distress. Together, this evidence suggests that CALD patients experience greater cancer burden and imply that there may be cultural and systemic barriers that impact on the CALD population in seeking and receiving suitable care in a timely manner.

This presentation will provide an overview of the issues faced by immigrant cancer survivors and directions for research to redress some of the identified inequities.

14

Issues for regional and rural cancer survivors

Kate Fennell[1]

1. University of South Australia, North Terrace, SOUTH AUSTRALIA, Australia

One third of Australians affected by cancer live in regional, rural or remote areas. They not only experience the challenges associated with a diagnosis of cancer in any setting, but also a number of additional stressors, largely as a result of their requirement to travel for treatment. This often comes with many social, emotional, practical and financial costs. The completion of cancer treatment and transition from urban centres back to rural communities can also present challenges for rural cancer survivors.

This talk will provide a brief overview of rural/urban disparities in cancer treatment outcomes and access to psychosocial care, and describe an online intervention, designed using Participatory Action Research to encourage rural South Australians affected by cancer to access relevant psychosocial support and optimal medical treatment.

Data on the differences between the self-reported health, mental health and health-promoting behaviors of rural and urban South Australian adults with a history of cancer (N= 4,295) will also be presented. These differences include rural cancer survivors' increased risk of diabetes, alcohol-related harm, obesity and limited engagement in physical activity, but greater trust in their communities and lower levels of self-reported psychological distress. The talk will conclude with the preliminary results of a qualitative exploration into what rural cancer survivors perceive as their greatest challenges after completing active treatment and returning home, and how they would like existing services to be reoriented and new services to be developed, so that their unmet needs are more appropriately addressed.

15

Population-level Approaches to Supporting Healthy Living in the Growing Population of Cancer Survivors

Catherine Alfano[1]

1. American Cancer Society, Washington, DC, United States

Randomized trials of exercise, diet, and weight management interventions for cancer survivors have shown these interventions have the potential to improve quality of life and reduce symptoms and treatment-related adverse health outcomes. Observational studies have also related inactivity and excess weight to increased risk of recurrence and second cancers and to reduced survival. Synthesis of this evidence has resulted in several clinical practice guidelines and policy statements from the American Cancer Society, American Society of Clinical Oncology, American College of Sports Medicine, and others that highlight the need for these interventions for all cancer survivors. Despite these guidelines, knowledge of the importance of these interventions for cancer survivors is low for survivors and clinicians, few survivors are engaging in healthy behaviors consistent with the guidelines, and programs to help survivors make healthy behavior changes are not widely available. This talk will review research, practice, and policy-level initiatives that have launched in the

United States to make personalized lifestyle prescription the standard of care for cancer survivors and help survivors make lasting behavior changes.

16

Supporting healthy living in the growing population of cancer survivors - engaging policy and practice partners

Elizabeth Eakin[1, 2]

1. Cancer Prevention Research Centre, SPH, University of Queensland, Herston, QLD, Australia

2. School of Public Health and Social Work, Queensland University of Technology, Brisbane, QLD, Australia

Background: Despite considerable evidence for healthy lifestyle interventions in cancer survivors, they are not incorporated into routine cancer care. In order to facilitate translation into practice, we engaged a range of cancer control policy and practice partners, including the Cancer Councils, State Ministries of Health and cancer clinicians.

Methods: This talk will describe the feasibility and patient-reported outcomes from two telephone-based lifestyle health coaching services that are being delivered in collaboration with cancer control partners: 1) Healthy Living after Cancer service (HLaC) is a six-month telephone-delivered program offered free of charge by Cancer Councils NSW, VIC, SA and WA targeting physical activity, healthy eating and modest weight loss and available to any adult cancer survivor treated with curative intent following primary treatment; 2) Get Healthy Service (GHS) is a similar six-month program offered by NSW Ministry of Health and available to any adult - here, we trialled its suitability for women following treatment for breast cancer. Thus, we are able to compare outcomes from a program tailored for cancer survivors to one targeting the general public.

Results: To date, the Cancer Councils have enrolled over 300 participants into HLaC (majority women with breast cancer), while the GHS was trialled with 53 women with breast cancer referred from a breast cancer clinic in NSW. The two programs show remarkably similar results, both with high participant satisfaction ratings, 62% program completion rates and weight loss of approximately 2.5kg. No serious adverse events were reported in either program.

Conclusions: While program participants and providers have a preference for cancer-specific programs, results here show that both programs can be safely and effectively delivered to achieve improvements in lifestyle in cancer survivors. With growing numbers of cancer survivors and a scarcity of preventive health resources, these results have important implications for cancer care delivery.

17

The role of general practice

Lyndal Trevena[1]

1. Sydney Medical School, University Of Sydney, NSW, Australia

With an increasing number of people surviving cancer, general practitioners are ideally placed to provide and facilitate a range of interventions to support healthy living in this group. This presentation will outline how current evidence could be integrated across the lifespan of cancer survivorship – from the short and longer term effects of treatment for adolescent and childhood cancer survivors through to managing chronic disease clusters and comorbidities in older cancer survivors. It will also provide a snapshot of survivorship activity in the most recent BEACH dataset and discuss results from the PROCARE study of share following prostate cancer treatment.

18

Healing and the Arts: Framing a Dialogue

David Joske[1]

1. Sir Charles Gairdner Hospital, Nedlands, WA, Australia

In response to the National Arts and Health Framework endorsed by the Ministers of Health across Australia in 2014, a Western Australian (WA) Arts and Health Consortium was established with leadership from St John of God Health Care and the WA Chamber of Arts and Culture. The Consortium consists of representatives from the public and private hospital systems, health consumers, arts advocates and the government departments of Health, and Culture and the Arts. A ground-breaking report[1] was commissioned to "map and measure the current level of engagement, support and investment in Arts and Health activities in order to better understand the extent to which the arts are contributing to the delivery of health services in WA hospitals and to the health and well-being of patients, their families, visitors and staff" (ibid, p6).

Key Findings. Whilst 75% of hospitals surveyed and interviewed indicated that they deliver Arts and Health activity, there was little evidence of overall co-ordination, strategy and planning. The top five barriers perceived by hospital staff were staff capacity, funding, space/time, co-ordination and patient safety; the top five issues identified by artists and arts organisations were staff capacity, time, hospital willingness, space and prioritisation of the arts organisation. There was little evidence of evaluation of arts in health projects, of induction training, and a focus on built environment and visual arts, rather than other media (performing arts, literary arts, participatory projects, and research).

Examples. There is growing awareness of the health benefits for patients, visitors and staff using these approaches. Examples include the UK "Breathe Magic" program[2,3,4] a program of teaching magic tricks to disabled and hemiplegic children that fosters bilateral muscle use. The Starlight X-ray Project at Princess Margaret Hospital, Perth, x-rayed children's favourite toys, giving children a greater sense of control of the hospital environment, and a channel for self-expression through story-telling with their images (ref 1, p55). Flinders Medical Centre provides an outstanding Model of care in Australia (ref 1, p68, refs 5, 6).

A Framework for Progress and Strategy Development. The report authors developed an Arts in Health Continuum based upon work by Putland[5,6]. The parameters for the Continuum include increasing levels of Activity (from art only used in hospital design and décor, through to art-making being part of hospital life), degrees of Readiness (escalating from minimal activity, to projects, to strategy, to a community of practice), degree of participant engagement, and artistic approach. The Continuum therefore identifies a process by which institutions and planners can seek to improve the use of Arts in Health, towards a mature strategically-planned practice widely involving the hospital community.

1. Gibson K, Goedhart L (June 2016). Examination of the use of the arts to improve health and healing in Western Australian Hospitals. The WA Chamber of Arts and Culture, June 2016. Accessible at http://www.instituteforcreativehealth.org.au/sites/default/files/arts_and_health_report_june_2016.pdf

2. Farquharson Y (2013, January 9) Breathe Magic 2012. (B. A. research, Producer) Retrieved may 10, 2016 from Youtube: https://www.youtube.com/watch?v=xVtujH_uu68
3. Farquharson Y (2016, April 14). Breathe Magic Case Study. Creative Arts in Hospitals. London, UK: Royal Society for Public Health.
4. Charles JG (2006). Development of hand-Arm bimanual intensive training (HABIT) for improving bimanual coordination in children with hemiplegic cerebral palsy. Developmental medicine and Child Neurology 48(11):931-6.
5. Putland, C (2012). Arts and Health. A Guide to the evidence. Arts and Health Foundation Australia.
6. Putland, C (2012). Arts in Health at FMC: Towards a Model of Practice. Flinders medical centre. Government of South Australia.

19

Emotional rescue

Elizabeth Jane Maher[1]

1. Macmillan Cancer Support, London, United Kingdom

I would never have thought that the Rolling Stones' music could have any impact on recovery from a bereavement but how wrong can you be!

20

Surviving through music

Jennifer Donovan[1]

1. Stylish Notes - Jenny Donovan, Glenelg South, SA, Australia

This presentation covers this latter period of my life and focuses on specific vignettes where music has acted as a conduit for change and healing for people I have worked with and for myself personally as a cancer survivor.

https://www.facebook.com/TherapeuticMusicJennyDonovan/

21

Song-writing as therapy

David Joske[1]

1. Sir Charles Gairdner Hospital, Nedlands, WA, Australia

Music therapy can be passive (listening) or active (playing). It has been shown, for example, to reduce depression scores in bone marrow transplant recipients and reduce length of hospital stay The expression of self and experience through the medium of music, allows for physical release and both unconscious and conscious story-telling, to relive or defervesce the experience of healing others. Thus the healer may heal themselves. In this brief session, I will try to show examples from my own experience as a songwriter.

Songs about health and ill-health and mortality are legion, from 1950s bluesman Earl Hooker's *There's a Fungus among Us* (he died of tuberculosis), to *Sister Morphine* by the Rolling Stones (mistakenly banned from radio play as "drug" song) to Chris Rea's stunning *Someday My Peace Will Come* from his Album *Dancing Down The Stony Road*, written mostly about his experience with pancreatic cancer.

Good music is entirely subjective, but involves the creation of musical tension and release. The songwriter must make choices: Major key (happy) or minor (sad)? Standard 4/4 time or ¾ (waltz, which creates a different feel and rhythm)? First person or third person voice? Slow or fast? Do you use a bridhe to expand or change the central idea? Protest songs (song: *Brave new World*) and love songs (song: *Symphony Song*) are an essential part of the singer-songwriter's musical vocabulary. A song might give form to the experience of being a health pioneer (song: *Trouble and Strife*). Or a song can sometimes recapitulate the healer's journey with a patient (song: *I Saw the Light Go Out In Your Eyes*).

Finally, I make no claim to being a great song-writer (I have won a WA Music Industry Award for my composition *Guilty As Charged*, so that gives me some credibility!), or having a great voice. That's not the point here! I see music as a uniquely human medium, as a great unseen radio station, accessible to all of us at any time to greater and lesser degrees. Music can melt barriers between people and within ourselves and as such play a key role in healing.

22

Willingness of cancer survivors to complete patient reported outcomes (PRO) surveys: a pilot study at Flinders Centre for Innovation in Cancer (FCIC), South Australia

Nadia Corsini[1], **Imogen Ramsey**[1], **Greg Sharplin**[1], **Michael Fitzgerald**[2], **Bogda Koczwara**[2], **Carlene Wilson**[1, 2], **Ingrid Flight**[1, 2], **David Roder**[3], **Marion Eckert**[3]

1. Cancer Council SA, Eastwood, SA, Australia
2. Flinders Centre for Innovation in Cancer, Bedford Park, SA, Australia
3. University of South Australia, Adelaide, SA, Australia

Background

There is a lack of population-level data on long-term outcomes following a cancer diagnosis aside from date and cause of cancer death. This could be remedied by routinely collecting patient reported outcomes (PRO) from cancer survivors.

Aim

The aim of this study was to determine acceptability of collecting PRO at baseline and 12 months later via a survey addressing psychosocial concerns post-treatment.

Method

The study setting was the FCIC survivorship clinic. Eligible patients had completed treatment with curative intent within three months. The Nurse Practitioner Candidate approached all eligible patients between October 2015 and July 2016 and obtained their verbal consent to be contacted by Cancer Council SA regarding participation. The primary outcome was response rate (the proportion of population approached that completed a survey; target 70%). Baseline results only are reported.

Results

47 patients were approached, 41 gave verbal consent (87.2%), 34 agreed to participate (72.3%), and 28 returned the survey (overall response rate = 59.6%). Reasons for declining at approach included: too distressed, life stressors and concern survey may trigger negative thoughts. Reasons for declining consent included family issues, not wanting to do survey, or were not provided. Participants reported that the survey covered personally important issues and there were few irrelevant questions.

Conclusions

Collecting PRO was challenging due to peoples' lack of readiness to engage at 3 months post treatment or loss of interest when contacted to participate. Response rate was below requirements for representative coverage. Participation may be improved by approaching people later and simplifying the approach and consent process. It is recommended that alternative methods are trialled to identify a sustainable approach to collecting PRO. This knowledge will enable identification of the burden and trajectory of long-term psychosocial outcomes following cancer treatment and will inform consumer centred support, advocacy and policy.

23

Evaluation of the effectiveness of Supportive Care Screening in rural ambulatory cancer care at Echuca Regional Health.

Lynette Jeffreson[1], **Cynthia Opie**[1, 2]

1. Echuca Regional Health, Echuca, VIC, Australia

2. Department of Rural Health, University of Melbourne, Shepparton, Victoria, Australia

Aim

To determine if cancer related distress can be identified through Supportive Care Screening (SCS) and mitigated through referrals to appropriate services.

Method

A mixed method descriptive cohort study using retrospective medical file audit data and self-report client questionnaires. Inclusion criteria: all patients receiving SCS from 20 December 2011 to 12 November 2015. Audit data recorded levels of distress as measured by a Distress Thermometer (DT) and associated causal issues. All living audited patients free from end stage palliation were mailed a questionnaire. Outcomes variables included current level of distress, satisfaction with the cancer service, attendance rates to supportive services and Quality of Life (EORTC QOL-C 30).

Results

Audit data showed a high distress (DT score of ≥ 4) rate of 40% (n=242) with peaks at diagnosis and end of treatment. High distress referral rates were low (n=28, 11.57%) amid overall low referral rates (n=80, 33%). Screening over time showed that high distress was not mitigated through referral to service providers.

Two hundred participants were sent the questionnaire, 104 responded (53% response rate). High distress was found in 32% (n=32). Patients self-reported high rates of service use. This was incongruent with the rate of referrals documented in the audit.

Men were more likely to be older; visited the health service more frequently; reported lower QoL measures; less satisfaction with the information provided about cancer; unlikely to see any positive benefits to having cancer; less likely to seek support groups and received lower numbers of referrals than women.

Conclusion

SCS accurately detects high distress. Overall referral rates are low, not predicted by distress and have not shown to mitigate high distress in this cohort. Timely referrals to the ambulatory cancer service are now sought, thus offering early intervention to ensure improved survivorship with an increased sensitivity to gender variance.

24

ACME – A Patient Reported Experience Measure (PREM) for Aboriginal people with experience of cancer.

Jasmine M. Micklem[1], **Harold B. Stewart**[1], **Janet Stajic**[1], **Marion Eckert**[2], **Paul Yerrell**[1], **Alex Brown**[1]

1. South Australian Health and Medical Research Institute, Adelaide, SA, Australia

2. Rosemary Bryant AO Research Centre, School of Nursing, University of South Australia, Adelaide, South Australia, Australia

Patient-Reported Outcome Measures (PROM) are used to measure patients' perceptions of both the impact of a condition and related treatment on their health[1], whilst Patient-Reported Experience Measures (PREM) broadly refer to a patient's experience with their care, including expectations, satisfaction, preferences, and values[2].

PROM/PREM feedback relates to: patient-clinician communication; patient challenges; and supporting clinical decisions by empowering patients' involvement in care. Such feedback is unavoidably heterogeneous. Variation principally relates to: PROM/PREM used and for what purpose; the healthcare setting; format and timing; and the population of patients. In this last respect, as yet, no PREM has been developed for or validated with Aboriginal people with experience of cancer.

Furthermore, there are challenges, understood by Community, to collation, interpretation and utilisation within the Aboriginal population, including: selection bias; recruitment across contexts; timing of data collection; and summarising information. Such context dependent feedback requires bespoke mechanisms for implementation.

To fill this gap in PREM provision, the Cancer Data and Aboriginal Disparities (CanDAD) Project has developed ACME – Aboriginal Cancer Measure of Experience. 64 semi-structured interviews with Aboriginal people with experience of cancer, carers/family members and service providers were analysed using patient pathway mapping and inductive thematic analysis. This included concerns and priorities of participants as they interact with the health system, located in the context of health system priorities as defined by South Australian optimal cancer care policies. Underlying themes, including barriers and enablers to care, were used to generate item-level statements within distinct phases of the cancer pathway, enabling ACME to focus on detection; treatment; and survivorship. Face and content validity were assessed with a group of stakeholders including the CanDAD Aboriginal Community Reference Group.

This presentation will demonstrate the construction and validation of ACME and identify its potential in reducing disparities in cancer through linkage with clinical data.

[1] Greenhalgh J. The application of PROs in clinical practice: what they are, do they work, and why? Qual.Life Res. 2009; 18(1): 115-23 doi: 10.1007/s11136-008-9430-6

[2]Chen J. Integrated care: Patient reported outcome measures and patient reported experience measures – a rapid scoping review. NSW Agency for Clinical Innovation.
https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0009/281979/ACI_Proms_Prems_Report.pdf Accessed 3rd October 2016.

25

Chemotherapy-induced peripheral neuropathy: Determining impacts on cancer survivors

Eva Battaglini[1], David Goldstein[2], Susanna Park[3]

1. University of New South Wales, Randwick, NSW, Australia

2. Medical Oncology, Prince of Wales Hospital, Randwick, NSW, Australia

3. Brain and Mind Centre, University of Sydney, Sydney, NSW, Australia

Chemotherapy-induced peripheral neuropathy (CIPN) is a major side effect of cancer treatments, and can result in long-term functional disability and reduced quality of life. However, the impact of CIPN on cancer survivors is poorly understood. Our aim is to investigate the impact of neurotoxic chemotherapy side effects on the health, physical activity, and quality of life of Australian cancer survivors. An anonymous online survey platform was developed addressing demographics, cancer diagnosis and treatment, the experience of CIPN and other side effects of chemotherapy, and included standardised measures to assess general health, quality of life, physical activity, neuropathy symptoms and pain. Analysis of 411 respondents (87% female; 13% male) with a median age of 58 years revealed a majority of patients treated for breast cancer (68%), with 10% of participants treated for multiple myeloma, 8% for colorectal cancer and 5% for ovarian cancer. The majority of respondents (78%) were currently experiencing neuropathic symptoms in the hands or feet. Greater severity of symptoms was reported in the feet – with 22% reporting 'very much' numbness or tingling compared to 11% for hands. In the 3.3 ± 0.1 years since completion of chemotherapy treatment (range 0-20 years), 28% respondents reported no improvement in symptoms. Accordingly, 51% of participants reported functional impact of CIPN on walking ability, 41% of participants reported impact on hand function and 58% indicated that they were limited in conducting vigorous physical activity. Neuropathy was rated as the cancer treatment side effect with the second greatest impact on participants' lives after fatigue, with 22% of participants reporting neuropathy as having the biggest impact on their lives. These findings indicate that CIPN has a lasting impact on cancer survivors and further work is required to establish best practice assessment, prevention and treatment approaches.

26

Internet support needs and preferences of women living with advanced breast cancer.

Lisa Beatty[1, 2], Emma Kemp[1, 2], Phyllis Butow[3], Afaf Girgis[4], Penelope Schofield[5], Jane Turner[6], Nick Hulbert-Williams[7], Janelle Levesque[8], Danielle Spence[9], Sina Vatandoust[10], Ganessan Kichenadasse[10], Amitesh Roy[10], Shawgi Sukumaran[10], Chris Karapetis[10], Michael Fitzgerald[10], Caroline Richards[10], Bogda Koczwara[1, 2]

1. Flinders University of South Australia, Adelaide, Australia

2. Flinders Centre for Innovation in Cancer, Adelaide, Australia

3. University of Sydney, Sydney , NSW, Australia

4. Ingham Institute for Applied Medical Research, University of New South Wales, Sydney , NSW, Australia

5. Swinburne University , Melbourne, Vic, Australia

6. University of Queensland, Brisbane, Qld, Australia

7. University of Chester, Chester, United Kingdom

8. Monash University , Melbourne, Vic, Australia

9. Breast Cancer Network Australia, Melbourne, Vic, Australia

10. Southern Adelaide Health Service, Bedford Park, SA, Australia

Aim

Metastatic breast cancer (MBC) is associated with significant distress but interventions for this population are lacking. This study summarises a mixed-methods study examining internet support needs and preferences of women with MBC including (a) internet use (b) information and support-seeking preferences and needs and (c) preferences for an internet-intervention to meet these needs.

Methods

Women with MBC recruited via clinicians or Breast Cancer Network Australia participated in (1) an online survey examining internet use for seeking cancer-related information and/or support (N = 43), (2) a telephone interview on current information and support needs (N = 11) and/or (3) a telephone interview regarding adaptation of an existing intervention for early-stage cancer patients, for women with MBC (N = 6).

Results

The majority of survey participants used the internet at least weekly to seek information/support (51%); while online support for treatment side effects (sought by 81%) was most commonly rated 'reasonably' or 'very' well covered, online support for fear of progression (sought by 65%) was most commonly rated inadequate (42%). The majority (81%) thought an online program for MBC information/support would be 'quite' or 'very' helpful. Preferred content included fact sheets (74%), online forums (65%) and survivor videos (63%). Interview participants indicated the following information as important to receive online: medical information (64%), sharing experiences of MBC (55%), coping with practical/system challenges (45%), well-being (36%), communicating with medical professionals (27%), diet and exercise (27%), and support for partners/family (27%). Participants who evaluated the existing program for EBC, recommended adding information on coping with ongoing treatment and mortality (83%), MBC-specific information (66%), more information on support for partners (66%), shorter modules (50%), and links to resources (33%). Updated results will be provided.

Conclusions

This study indicates need and scope for an internet-intervention to provide information and support to women living with MBC.

27

‘How long is the piece of string?’ – How patients negotiate the uncertainties of a Neuroendocrine tumour diagnosis

David Wyld[2, 1], **Stefanie Plage**[3], **Matthew Burge**[2, 1], **Alex Broom**[3], **Zarnie Lwin**[2, 1], **Helen McDade**[2], **Annette Cubitt**[2]

1. School of Medicine, University of Queensland, Brisbane, Queensland, Australia

2. Department of Medical Oncology, Royal Brisbane Hospital, Herston, QLD, Australia

3. School of Social Sciences, University of New South Wales, Sydney, NSW, Australia

Aims

The aim was to explore challenges patients with Neuroendocrine Tumours (NETs) face due to their incurable but slow-growing nature.

Methods

Semi-structured interviews with 30 patients (12 female, 18 male) treated for NETs at a hospital in Queensland, Australia. The data was analysed using NVivo10.

Results

4 major themes emerged. (1) Despite the poor long term prognosis a proportion of participants sought to adopt a positive outlook or denied the severity of their condition; (2) On reflection, symptom management was accompanied by uncertainty about available treatment options, disease progression, quality of life and life expectancy; (3) Participants perceived contradictions in how their NET prognosis was framed by different health professionals involved in their care; (4) Some participants expressed feelings of fear, guilt and social isolation due to the uncertainties of the NET diagnosis.

Conclusions

We highlight challenges for NET patients to resolve the tension between a terminal prognosis and a slow but unpredictable disease progression. They often struggle to explain their condition to significant others or fully understand the nature of their illness themselves. This is exacerbated by – and in turn exacerbates - the limited public awareness of NETs inviting some to lead ‘double lives’ in which NETs are dealt with secretly. Improved expertise among health professionals and communication with patients and their families to enhance the recognition of NETs could potentially alleviate these issues.

28

How confident would you be? An analogue study of interpersonal and situational factors influencing caregiver self-efficacy in the context of advanced cancer

Katriona M Smith[1], **Kerry Sherman**[1]

1. Macquarie University, NEW SOUTH WALES, Australia

Aims: Caring for an individual with advanced cancer is a challenging and stressful experience for most caregivers. However, little is known about how individual and situational factors related to caregiving influence perceived caregiver self-efficacy. This analogue study investigated the impact of the valence of care recipient demeanour and perceived medical support on caregiving self-efficacy and expectations of care recipient behaviour.

Methods: Australian adults (N=135; mean age 48.05 years, 20% male) with no prior cancer caregiving experience were recruited for the online 2 x 2 analogue study via social media and snowball sampling via personal email contacts. Participants were randomly assigned to receive information about one of four hypothetical scenarios regarding caring for a mother with advanced cancer. Scenarios varied by the valence of the care recipient (positive/negative) and perceived supportiveness of her medical care team (supportive/unsupportive). Participants completed post-manipulation measures of perceived caregiving self-efficacy and expectations of care recipient behaviour.

Results: Bootstrapped multivariate analysis of covariance (controlling for age, prior caregiving experience, positive reappraisal, social support, and attitude to dying) revealed a significant main effect for condition ($F=8.80$, $p<.0005$). Individuals assigned to the positively valenced care recipient reported higher caregiving self-efficacy and had more positive expectations of care recipient behaviour than those assigned to the negatively valenced care recipient. There were no differences between individuals assigned to supportive or unsupportive medical care.

Conclusions: These results indicate that the negative valence of a care recipient towards their caregiver is associated with decreased caregiving self-efficacy in a hypothetical caregiving scenario. Therefore, if this effect is confirmed amongst current caregivers of individuals with advanced cancer, consideration should be given to interventions which will mitigate the impact of negatively valenced care recipients, and bolster caregiving self-efficacy.

29

Let’s talk about sex – in conversation with a Rekindle study participant

Haryana Dhillon[1], **Douglas Williams**[1], **Phyllis Butow**[1], **Ilona Juraskova**[1], **Kim Hobbs**[2], **Annie Miller**[3], **Catalina Lawsin**[4]

1. Centre for Medical Psychology & Evidence-based Decision-making, Central Clinical School, Sydney Medical School, The University of Sydney, Sydney, NSW, Australia

2. School of Public Health, University of Sydney, Sydney, NSW, Australia

3. Crown Princess Mary Cancer Care Centre, Westmead Hospital, Westmead, NSW, Australia

4. School of Information Technology, University of Sydney, Sydney, NSW, Australia

Background

Many people diagnosed with cancer experience changes in sexual function due to disease and/or side effects of treatment. Long-term sexual changes can lead to psychological distress and reduced quality of life for survivors and partners. We developed and piloted *Rekindle,* a web-based psycho-educational intervention, to provide accessible, tailored psychosexual support to cancer survivors

Objectives: to explore the experience of taking part in the rekindle program study.

Intervention:

The Rekindle study is a 3-arm phase II randomised control trial conducted over six months.

Treatment groups: Rekindle, Rekindle Plus (self-led plus 3 navigational support calls) and Attention Control.

The Rekindle intervention incorporates seven evidence-based modules empowering users to manage sexual changes, content is delivered via the internet as written information, video, tutorials, and exercises. Two modules are mandatory and five tailored to user’s sexual concerns. *Rekindle* is tailored to gender, patient/partner, single/partnered, and sexual preference requiring a total of 12 versions of materials, all subject to individualised prescription of modules. Attention control participants are provided written information via the internet during the first 10 weeks, then given access to Rekindle.

Results: 105 people took part in the Rekindle study between October 2015 and November 2016. Here we will conversationally explore an individual's experience of the study and intervention, as well as their experience discussing sexual worries or problems with their healthcare providers both before and after their cancer experience to see how this might have changed since completing the study. We will also explore the impact of healthcare provider behaviours that either facilitate or block conversations about sexual health.

Conclusions: Many cancer survivors report difficulty in raising sexual concerns with their healthcare providers. It is important for providers to facilitate conversations about sex by giving patients permission to ask questions about their sexual health and wellbeing.

30

Fertility preservation

Antoinette Anazodo[1]

1. Sydney Youth Cancer Service, Fairlight, NSW, Australia

Abstract not available at time of print.

31

Family matters: How cancer impacts parents, partners, offspring, and siblings?

John Friedsam[1], **P Patterson**[1], **F.E.J. MacDonald**[1]

1. CanTeen, Sydney, NSW, Australia

The psychosocial impact of cancer on adolescent and young adult (AYA) patients is substantial and well-established. There has also been an increased focus on psychosocial difficulties extending into survivorship, with higher levels of depression, anxiety, post-traumatic stress, and distress commonly reported amongst AYA survivors. In addressing the supportive needs of this age group, it is important to consider their place in the family context. Parents, siblings, and partners can help young patients adjust to the impact of their cancer and this support has been associated with improved psychosocial outcomes. However, poor family functioning can intensify the negative impacts of cancer. Moreover, AYAs who are not patients themselves can also be negatively impacted by familial cancer if a parent, partner or sibling is diagnosed, and can even experience higher levels of distress than the patient. This impact can also extend into survivorship. Considering familial influences and supporting the family are important considerations in strengthening patients' wellbeing. This presentation will focus on ways in which family members can be practically supported.

32

The financial burden of cancer – an unspoken side effect of cancer

Bogda Koczwara[1]

1. Flinders Centre for Innovation in Cancer, Bedford Park, SA, Australia

The financial burden of cancer, or so called financial toxicity, is increasingly recognised as an important issue for cancer patients and survivors, as well as their families with impact not only on quality of life but overall survival. While it is often assumed that the main reason for financial burden is high cost of unfunded cancer drugs, other costs, for example transport and private insurance co-payments are also significant concerns. In addition, inability to maintain employment at the pre-diagnosis level appears to be the major driver of financial burden. For patients who are already socioeconomically disadvantaged, the additional financial burden of cancer treatment, significantly amplifies their already vulnerable state.

There is a need for accurate measurement of financial burden of cancer, adequate disclosure of its risks and development of effective strategies to address them. This presentation will review existing data on the financial burden of cancer and propose recommendations for clinical practice and research to address this major concern.

34

Minding the Gap – Consumer led programmes can fill a much needed Cancer Related Lymphoedema management space

Monique Bareham[1], **Ruth V Klee**[1]

1. Lymphoedema Support Group of South Australia (LSGSA), Port Augusta, SOUTH AUSTRALIA, Australia

Cancer Related Lymphoedema is a major area of concern for many Cancer Survivors. Peer support for Cancer Survivors is an important component of living the "new normal" positively. Our consumer led group, the Lymphoedema Support Group of South Australia (LSGSA) is committed to providing education, information and advocacy to anyone at risk or living with the condition in the state.

The current situation for Lymphoedema patients in South Australia is dire: there is a lack of clear referral pathways, limited availability for assessment and treatment clinics and financial support (government subsidies) for compression garments is lacking.

There appears to be confusion within the medical fraternity regarding appropriate Lymphoedema management procedures leading to too many consumers being given misinformation, misdiagnosis and inadequate treatment. Consumers can become overwhelmed as to how best to manage their condition in the early stages. This leads to a worsening of the condition, heightened risk of developing associated illnesses and negative psychosocial impacts on the individual.

In response to many concerns raised by consumers and therapists alike through our network, we endeavoured to plug this gap. The LSGSA collaborated with accredited Lymphoedema therapists, Breast Care nurses and Lymphoedema researchers to hold a "Breast Cancer Related Lymphoedema Information and Awareness" day in Feb 2016. Attended by both consumers and therapists from city and country areas, it was a great success!

The LSGSA plans to be more inclusive of all cancer related Lymphoedema patients with our programme planning sessions in 2017. Themed information and awareness events highlight the way consumer led, medical practitioner supported education programmes combined with peer support can positively impact the daily challenges of cancer survivors.

35

Peer support volunteers with advanced cancer: meeting unique needs on the survivorship continuum

Fiona McRae[1], **Wendy Pullan**[1], **Kellie Holland**[1]

1. BREACAN, MELBOURNE, VIC, Australia

Introduction

In 2003, as the BreaCan service began, women with advanced cancer wanted to access the service and to contribute as volunteers. Women told us that they:

- Felt isolated from family, friends and women with early cancer diagnoses
- Wanted to live life as well as possible
- Wanted to contribute to their community
- Had physical health issues
- Were fearful of what death looks like

Speaking with women we know that many still experience these same emotions in 2016.

Description

BreaCan's dedicated program for women with advanced cancer involves the recruitment, training and support of women with advanced cancer as peer support volunteers. The program also involves information sessions that enable women with advanced cancer to learn more about living with cancer, share their experiences and feel less isolated.

BreaCan has recruited more than ten women with advanced cancer and a further eight women have been re-diagnosed whilst volunteering. In 2015/16, BreaCan had 169 women who had identified they had advanced cancer on their mailing list.

How these volunteers help BreaCan?

These volunteers:

- Share their understanding of advanced cancer with other women
- Educate and support other volunteers and staff about the diversity of cancer experience
- Keep BreaCan's organisational ethos and policies mindful of and relevant to, the needs of women with advanced cancer.

These volunteers also gain support, information and sense of contribution from BreaCan.

Conclusion:

Including women with advanced cancer as volunteers at BreaCan has enabled a program of support to be available to women who:

- Are often not included in program delivery
- Can be excluded from other groups

Service users benefit from seeing these volunteers commitment to living life as well as possible.

The death of volunteers affects all who volunteer and work at BreaCan. These times require sensitive management and a commitment to ensuring their contributions are honoured appropriately.

36

Reflections on my experience as a survivor

Courtney Oake

At the age of fourteen, I was diagnosed with Acute Lymphocytic Leukaemia (ALL) having been continuously unwell with colds for around six months. After two years of intensive treatment including both chemotherapy and radiotherapy throughout my final years at high school, I was given the all clear and went on to study at University. I was actively involved with CanTeen until the age of 20 when I moved interstate and made the decision to go out on my own. The unwavering support from my peers at this organisation helped me greatly in developing my self-confidence and enabled me to become the person I am today.

Having a diagnosis like leukaemia as a teenager changed me and it helped to plan my future path both from a professional and from a personal perspective. I became a qualified Radiation Therapist and worked in different capacities both here in Australia and overseas and consequently was lost to traditional follow up. Through professional contacts and my own self-awareness I arranged to attend a Late Effects clinic in Adelaide at the Women's and Children's Hospital (WCH) and an endocrinology clinic in the United Kingdom where I was living and working.

In 2015 I was diagnosed with radiation induced meningiomata on the left side of my brain. After an eventful surgery and ongoing recovery, I am a two time survivor whose life has again been shaped emotionally, practically, financially and socially by my experience, and living with the knowledge that it could happen again.

This presentation will address the impact the diagnoses have had on my life and also the need for ongoing follow-up for long term survivors.

40

Interventions for health and well-being in adolescents and young adults after cancer: a systematic review

Natalie Bradford, Raymond J Chan

Purpose: To identify, appraise and synthesis the effects of physical and physiological post-treatment interventions for adolescents and young adults (AYAs) with cancer.

Methods: A systematic review was undertaken using the preferred reporting items for systematic reviews and meta-analyses guidelines. Included studies were identified though a range of electronic databases through to May 2016. Studies were critically appraised using the Cochrane Risk of Bias tool

Results: Fifteen studies, comprising a total of 2016 participants were included in this review. Eight studies were randomized controlled trials (RCTs), the remaining seven were before and after studies. The quality of studies was variable across all appraised domains with risk of bias evident in regards to recruitment, measures of exposure and outcomes, confounding factors and lost-to follow-up. Studies evaluated a range of physical, psychological and educational interventions to improve health related and process outcomes. Ten studies reported modest positive outcomes, with physical and psychosocial interventions achieving greater success than educational interventions.

Conclusions: This review highlights the lack of high-quality studies for improving the health and well-being of AYA cancer survivors. No conclusive evidence favouring specific interventions were identified, although recommendations for future studies are made.

Implications for Cancer Survivors: Interventions to support AYAs after treatment for cancer are required to promote health and well-being, and to address the array of psychosocial concerns in this population. Rigorous, properly powered RCTs are required to identify the optimal methods of delivering interventions to support AYAs after cancer treatment.

41

Fertility issues in young people after cancer: what do I need to know?

Natalie Bradford[1], Roslyn Henney[1], Rebekah Orford[1], Raymond Chan[2]

1. Youth Cancer Service, Children's Health Queensland, South Brisbane, QLD, Australia

2. Queensland Health/ QUT, South Brisbane, QLD, Australia

Background: In adolescent and young adult (AYA), the effects of cancer and treatment on fertility can be a continuing source of distress. Young people with cancer rely upon clinicians to provide information and advice regarding fertility preservation options.

Objectives: This study aimed to explore health professionals current practice, knowledge and understanding of fertility preservation options, and explore the barriers to fertility preservation for AYAs with cancer.

Method: A cross sectional survey was undertaken with health professionals across Queensland involved in the clinical care of AYAs with cancer.
Results: Eighty-five responses were received from medical (n=23, 27%), nursing (n=59, 69%) and allied health staff (n= 5, 6%) from staff across major cancer centres in Queensland. Forty-four respondents (55%) routinely discussed risk of infertility with AYA patients. Most respondents provided verbal information only. Eighteen (22%) respondents routinely provided written or audio visual information. The main barriers identified in providing information and undertaking a discussion of risk of infertility were: lack of clinical skills and knowledge regarding fertility (49%); the clinical presentation of the patient and urgency for treatment (38%); time (37%), and a lack of supporting information and educational resources (36%). Most respondents rated their knowledge of specific fertility preservation options as average or poor, and 71 (85%) health professionals responded they required more knowledge about fertility preservation options.
Conclusion: These findings highlight the need for clearer referral pathways and education regarding fertility preservation for AYAs with cancer. Fertility is a great concern in this population, and post treatment, can have long term effects on quality-of-life. To provide high quality care in this domain, health professionals need access to clear guidelines, education and information.

42

Establishing an integrated state-wide adolescent and young adult cancer service

Natalie Bradford[1], Roslyn Henney[1], Po Inglis[2], Rick Walker[1]

1. Youth Cancer Service, Children's Health Queensland, South Brisbane, QLD, Australia

2. Cancer Services, Metro North HHS, Brisbane, QLD

Background: Worldwide attempts have been made to improve the outcomes for adolescents and young adults (AYA) diagnosed with cancer by developing dedicated programs and services. These services are imperative to optimise the health and well-being of the ever increasing numbers of AYA cancer survivors. In Australia, Commonwealth funds established a National Youth Cancer Network Program in 2009. CanTeen Australia coordinates the Youth Cancer Service (YCS) program and five jurisdictional lead sites are now established in Melbourne, Brisbane, Adelaide, Sydney and Perth. Queensland's vast state and widely dispersed population presents unique challenges to providing coordinated access for youth cancer across this landscape.
Objectives: To describe the development and outcomes of the YCS in Queensland.
Methods: The central team based in Brisbane at the Lady Cilento Children's Hospital, partners collaboratively with five tertiary cancer centres located across the state. In a consultative partnership model with primary oncology treating teams, the central team collaborates and coordinates activities to facilitate equity in access to AYA specific services. The QYCS receives approximately 150 new AYA referrals each year and provides ongoing support in survivorship to around 350 AYAs annually. Approximately 50% of patients live in the metropolitan area with the remaining from regional and rural locations. Care coordination and workforce development is managed using technology including video-conferencing and web-based data systems. All YCS clinical activities are documented in the data system, enabling patient information to be retrieved in all locations across the state.
Results: Review of service activity during 2015 identified 100% (n=347) of patients were presented at a psychosocial, multi-disciplinary team (MDT) meetings, and 66% of patients at medical or surgical MDTs. Fertility preservation information was provided to 78% of patients, 15% were enrolled on a clinical trial and 40% received additional vocational or educational support.
Conclusions: The re-design of a health service is a challenging and complex task. These outcomes highlight the success in certain aspects of the cross-institutional, collaborative model, and provide a benchmark to measure improvement.

43

Patient-clinician discussions about fertility in the adolescent and young adult cancer population: A multi-centre retrospective study

Roslyn Henney[1], Natalie Bradford[1], Po Inglis[2, 1], Rick Walker[3], Raymond J Chan[2, 4]

1. Queensland Youth Cancer Service, Children Health Queensland, Brisbane, Australia

2. Royal Brisbane and Women's Hospital, Herston, QLD, Australia

3. Lady Cilento Children's Hospital, Brisbane, Queensland, Australia

4. Queensland University of Technology, Brisbane , QLD, Australia

Aims: In the adolescent and young adult (AYA) groups, effects of cancer and treatment on fertility can be a continuing source of distress. The study aims to explore factors that may influence discussions regarding fertility in this population.

Methods: A three year retrospective review (2012-2014) of medical records of young cancer patients aged 14-25 years, was undertaken in five cancer centres affiliated with the Youth Cancer Service in Queensland. Data were extracted, risk ratios (RR) calculated and analysis undertaken with chi-square statistic.

Results: Medical records of 347 patients were reviewed. According to these records, 217 (61%) patients had received gonadotoxic treatment. Of these patients, males (n=128) were significantly more likely to receive gonadotoxic treatment than females (n=89), (RR 1.3, p=0.003); have a documented risk of infertility discussion (RR 1.3 p=0.005), and to have documented fertility preservation (RR 2.4, p=<0.001). Sperm cryopreservation was documented in 67 (52%) of males. Sixteen (18%) females had documented ovarian suppression prescribed. Oocyte and embryo preservation was documented in six females. Compared to other diagnoses, patients with soft tissue sarcomas (n=15) were the least likely to have risk of infertility discussions documented (RR 0.46, p=<0.03), and Non-Hodgkin's lymphoma (n=23) were the most likely (RR 1.35, p= <0.001).

Conclusions: We acknowledge the limitation of our findings due to the retrospective nature of the study. The findings highlight important differences, with inferences as to why some disparities exist. It also suggests that fertility discussion may be highly dependent on tumour type and the technicalities of preservation techniques.

44

The Bridge of Support - A collaborative approach to a peer support program

Robin D Curwen-Walker[1], Meron Pitcher[2], Melanie Fisher[2], Kylie Barton[2], Leanne Storer[2]

1. BreaCan, Melbourne, VICTORIA, Australia

2. Breast Clinic, Western Health , Melbourne, Victoria

BreaCan's Bridge of Support Program at Western Health aims to adapt a community-based model of peer support into the acute setting to meet the diverse needs of women with breast cancer in Western Health's catchment area. This acute-community sector partnership demonstrates how the medical and social models of health can work in harmony to provide a connected and quality service for women. Key elements of the successful collaboration include:

- an enduring, respectful relationship between Western Health and BreaCan
- shared values of diversity, responsiveness and accessibility
- champions within the acute setting
- an MOU outlining responsibilities of all partners
- representation of key stakeholders, including peer support volunteers on the project steering committee
- a dedicated project officer supporting volunteers and project partners
- an action research approach allowing the project to be responsive to issues and challenges as they arise

The program has been operating since February 2016 and the initial data (Feb-Aug 16) indicates some positive early results:

- 41 individual women treated for breast cancer accessed the program (82 separate contacts)
- figures for Western Health's breast service for the same period are not yet available, however based on previous year's data this represents an estimated reach of approximately 40% of women seen by the breast service.
- 50 per cent of the contacts were follow-up contacts with BreaCan volunteers either at the hospital or through BreaCan's resource centre, demonstrating a successful bridge to community-based peer support
- 20 per cent of women had metastatic disease enhancing access to support and information by women with advanced cancer
- 61 per cent of women were born in non-English speaking countries (compared with 17% in Victoria overall) reflecting an accessible service.

Importantly clinicians noted the value of a service which complements medical treatment, giving space and time to patients. It is particularly helpful for women with complex information needs.

45

A new model supporting best practice follow-up care for early breast cancer in Australia: shared follow-up care for early breast cancer

Carolyn Der Vartanian[1], Katrina Anderson[1], Karen Evans[1], Cleola Anderiesz[1], Christine Giles[1], Helen Zorbas[1]

1. Cancer Australia, Surry Hills, NSW, Australia

Introduction

Guidelines recommend long term follow-up for women after breast cancer treatment.[1] As breast cancer incidence increases and survival rates improve, progressively more women will require follow-up care. New models of care are required to address the increasing demand on the specialist workforce.

Aim

This program aimed to evaluate the extent to which shared follow-up care for early breast cancer (EBC) supports best practice and identify the comparative cost of shared follow-up care for EBC in a general practice setting compared to a specialist-led setting.

Method

Following a demonstration of shared follow-up care for EBC (2009-2011), an evaluation to assess the extent to which the model supports the delivery of best practice follow-up care was conducted (2013-15). Follow-up appointments involving 580 patients across five sites were documented over a two year period and analysed. An economic evaluation and financial impact model were used to estimate the national costs of EBC follow-up care in the general practice and specialist-led settings using an epidemiological approach.

Results

The majority of shared care follow-up visits included completion of key examinations and actions in accordance with guideline recommendations. Mammograms were provided to 73% of patients at least annually, in accordance with guidelines. Compared to specialists, a significantly higher proportion of general practitioners reviewed psychosocial issues, family history, menopausal status, and other health conditions, and discussed secondary prevention behaviours. The examination of potential cost savings showed that over a lifetime (20, 25 or 30 years) of follow-up care, a shared care model is more cost-efficient than the specialist-led model, and also frees up specialist hours.

Conclusion

Cancer Australia's evaluations demonstrated that shared follow-up care for EBC is delivered in accordance with guidelines. There are also cost and time savings translatable to additional and earlier patient care that can be achieved if shared follow-up care is implemented.

[1] National Breast and Ovarian Cancer Centre. Recommendations for follow-up of women with early breast cancer. Surry Hills. NBOCC, 2010.

46

Exercise during cancer treatment: A pilot survey of what Australian Cancer Health Professionals think.

Jane D Turner[1, 2], Michael Marthick[3], Haryana M Dhillon[1]

1. Centre for Medical Psychology and Evidence-based Decision-making, The University of Sydney, Sydney

2. Concord Cancer Centre, Concord, NSW, Australia

3. Chris O'Brien Lifehouse, Camperdown, NSW, Australia

Background

In people treated for cancer, physical activity (PA) is known to decline. For most people their PA never returns to pre-diagnosis levels. PA reduces incidence of cancer, severity of treatment related symptoms, improves quality of life and mood, maintains muscle mass, strength and functional status. Despite these benefits, there are few PA/exercise programs available for cancer patients particularly during treatment. Views of Australian health professionals about exercise in cancer patients before, during and after treatment are unknown.

Objective

To pilot a survey designed to determine the perceptions of Australian oncology health professionals about exercise in people diagnosed with cancer undergoing treatment.

Methods

We used a pilot, cross-sectional study design to survey a convenience sample of health professionals working at two Cancer Centres in Sydney. Descriptive statistics are reported.

Results

The survey was completed by 71 respondents across 13 disciplines (24% medical oncology, 20% nursing, 11% radiation oncology). Most (88%) reported engaging in regular exercise themselves. Majority of professionals agree/strongly agree exercise is beneficial (78%), safe (78%) and important (77%) during cancer treatment. They believe their patients are capable of exercising (67%) and recommendations would be well received (74%). Only 5% disagreed/strongly disagreed that patients should exercise during treatment. Many (64%) spend 1-5 minutes discussing exercise in consultations; 25% do not discuss exercise. 56% refer their patients to within hospital exercise programs. Barriers to referral include patient factors (fatigue/pain 56%), too many things to discuss (46%), financial constraints (37%) and their own knowledge of exercise prescriptions (37%).

Conclusion

This study reports that Australian oncology health professionals perceptions of exercise are likely to influence advice given to patients. The findings indicate cancer health professionals agree that exercise is important and beneficial for patients throughout treatment. This pilot study is being rolled out across Australia through oncology professional groups.

47

Fear of cancer recurrence and psychological well-beingin women with breast cancer: The role of causal cancerattributions and optimism

Jo Anne R Dumalaon[1], Ivanka Prichard[2], Amanda Hutchinson[3], Carlene Wilson[1]

1. Flinders Centre for Innovation in Cancer, Adelaide, SA, Australia

2. School of Health Sciences, Flinders University, Adelaide, SA, Australia

3. School of Psychology, Social Work and Social Policy, University of South Australia, Adelaide, SA, Australia

Aims

This study aims to examine the association between cancer causal attributions, fear of cancer recurrence (FCR) and psychological well-being and the possible moderating effect of optimism among women with a previous diagnosis of breast cancer.

Methods

Participants (N = 314) completed an online self-report assessment of causal attributions for their own breast cancer, FCR, psychological well-being, and optimism. Simultaneous multiple regression analyses were conducted to explore the overall contribution of causal attributions to FCR and psychological well-being separately. Hierarchical multiple regression analyses were also utilised to examine the potential moderating influence of dispositional optimism on the relationship between causal attributions and FCR and psychological well-being.

Results

Age, ethnicity, breast cancer stage at diagnosis, optimism, and the extent to which cancer was attributed to environmental exposures, family history, and stress were significant predictors of FCR (R^2 = .263, F (16, 281) = 6.28, p < .001). Breast cancer stage at diagnosis, optimism and the attribution of stress emerged as significant predictors of psychological well-being (R^2 = .310, F (16,281) = 7.90, p < .001). Optimism did not moderate the relationship between causal attributions and FCR or well-being.

Conclusions

The observed relationships between causal attributions for breast cancer and FCR and psychological well-being suggest that the inclusion of causal attributions in screening for FCR is potentially important. Health professionals may need to provide greater psychological support to women who attribute their cancer to non-modifiable causes and consequently continue to experience distress.

48

Transition of childhood cancer survivors to adult survivorship care: survivor preferences, and barriers to care

Joanna E Fardell[1, 2], **Beeshman S Nandakumar**[1, 3], **Claire E Wakefield**[1, 2], **Christina Signorelli**[1, 2], **Jane Skeen**[4], **Ann M Maguire**[5, 6, 7], **Jordana K McLoone**[1, 2], **Richard J Cohn**[1, 2]

1. Kids Cancer Centre, Sydney Children's Hospital, Randwick, NSW, Australia

2. Discipline of Paediatrics, School of Women's and Children's Health, UNSW Medicine, University of New South Wales, Randwick, NSW, Australia

3. University of New South Wales, Randwick, NSW, Australia

4. Starship Blood and Cancer Centre, Starship Children's Hospital, Auckland, New Zealand

5. Discipline of Child and Adolescent Health, The University of Sydney, Sydney, NSW, Australia

6. Long Term Follow Up Clinic, Department of Oncology, The Children's Hospital at Westmead, Sydney, NSW, Australia

7. Institute of Endocrinology and Diabetes, The Children's Hospital at Westmead, Sydney, NSW, Australia

Aim: Long-term survivorship care is recommended for childhood cancer survivors (CCS) to manage life-long treatment-related 'late effects', including complex medical, cognitive or psychosocial issues. Ongoing paediatric-based care is often not possible, requiring CCS to transition into adult-based survivorship care. This study describes CCS' preferences and barriers to transition to adult-based survivorship care.

Method: CCS and parents (of survivors <16 years) from 11 hospitals around Australia and New Zealand were surveyed (*stage 1*) and interviewed (*stage* 2) regarding their transition experiences.

Results: *Stage 1:* 295 CCS (mean age 26.3years) and 173 parents (survivor mean age 13.5years) were surveyed. Eighteen years old was the most commonly preferred age for transition nominated by survivors (38.9%) and parents (49.2%). A significant minority of survivors (10.5%) and parents (7.6%) reported preferring never to transition out of paediatric specialised follow-up care. Survivors who received radiotherapy were more likely to report a preference for never transitioning (p=.012). No other treatment or clinical variables, or number of current health concerns, were associated with preferred transition age. Perceiving a high risk (p=.019), and reporting greater worry (p=0.038) about late effects were associated with preferring to never transition. *Stage 2:* In 33 interviews (n=18 survivors, n=15 parents), participants described positive (55%), neutral (15%), or negative (30%) attitudes towards transition. Many survivors were not aware that a transition to adult services would occur, and key barriers included over-dependence on paediatric carers, a lack of confidence in adult-based practitioner's familiarity of their cancer-related history, inadequate communication and information about survivorship care, and cognitive difficulty.

Conclusions: Given the choice, some survivors may be reluctant to transition out of pediatric-based follow-up. In preparing survivors for transition, survivors' worry about late effects, communication and confidence in their new survivorship care team should be considered to ensure they remain engaged in essential lifelong follow-up care.

49

Documenting health service inequities and identifying potential criteria for addressing them: A case study of breast reconstruction in Australia.

Kathy Flitcroft[1, 2], **Andrew Spillane**[1, 2], **Meagan Brennan**[1, 2]

1. Breast & Surgical Oncology at The Poche Centre, North Sydney, NSW, Australia

2. Northern Clinical School, The University of Sydney, St Leonards, NSW, Australia

Introduction: Access to breast reconstruction (BR) following mastectomy for breast cancer is an important aspect of survivorship for many women. Although up to 50% of women would choose to have BR if offered it, previous estimates of BR rates within Australia range from 8 to 16%.

Aim: To clarify the BR rates between and within regions of Australia and to report breast care nurses' (BCNs) views on local barriers to BR.

Methods: Data sets from the BreastSurgANZ Quality Audit (BQA) and geospatial software were used to model the national and intra-state distribution of BR procedures performed on patients of BreastSurgANZ members in Australia in 2013. Data were analysed using chi-squared tests of independence. A survey of BCNs provided a snapshot of BR practice in 42 locations across Australia, including their views on the most significant barriers to BR access in their local areas.

Results: Analysis revealed a national BR rate of 18.3%. Statistically significant differences in BR uptake (p<.0001) were found between jurisdictions [χ^2(df=7)=284.29], with BR more likely in younger women [χ^2(df=14)=395.62] and in private hospitals (χ^2= 63.99) and less likely in remote areas [χ^2(df=4)= 66.49] and non-capital city areas within states [χ^2=144.60]. BR was not reported in over 40% of hospitals where mastectomy was conducted by members of BreastSurgANZ, including 30% of hospitals within capital city regions. Analysis of the BCN survey data identified the most significant barriers to BR were cost, distance to travel, inadequate numbers of specialist breast and plastic surgeons and lack of theatre time. 42.5% of BCN respondents reported no BR was available in their city/town.

Conclusion: Access to BR services varies widely across Australia and barriers are multifaceted. This presentation concludes with a policy discussion of what factors should be considered in determining a feasible and acceptable distribution of BR services.

50

The relationship between resilience, distress and quality of life in cancer patients and survivors

Corinna Freytag[1], **Lisa Beatty**[2], **Bogda Koczwara**[3]

1. School of Psychology, Flinders University, Adelaide, South Australia, Australia

2. School of Psychology, Flinders University, Adelaide, South Australia, Australia

3. Medical Oncology, Flinders University and Flinders Centre for Innovation in Cancer, Adelaide, South Australia, Australia

Aims

Resilience is defined as a quality that, when high, enables people to (1) maintain higher levels of quality of life (QOL) throughout times of adversity, such as living with cancer, and (2) recover more quickly from the distress associated with the adverse event. On the foundation of the Broaden-and-Build Theory of Positive Emotions, this study investigated whether resilience moderates the relationship between QOL and distress.

Methods

Cancer patients (n=51) either currently receiving treatment ('mid-treatment'), or post-treatment were recruited from a single institution. Patients completed a questionnaire battery comprising demographic and medical information; general distress (Depression Anxiety and Stress Scale); cancer-specific distress (Posttraumatic Stress Scale - Self Report); resilience (Connor-Davidson Resilience Scale); and QOL (European Organisation for Research and Treatment of Cancer Quality of Life Core Questionnaire). Three multiple hierarchical regression analyses were conducted to test the hypothesised moderation.

Results

The relationship between QOL and distress did not differ between highly or less resilient patients ($R^2_{change} = .017$, $F_{change}(1, 44) = 1.020$, $p = .318$). QOL was negatively associated with distress levels regardless of resilience levels. Results provided tentative support for the hypothesis that high resilience is associated with a faster recovery from distress ($R^2_{change}=.063$, $F_{change}(1,43)=3.444$, $p=.070$), as highly resilient patients reported lower distress across both mid- and post-treatment. Less resilient participants were more distressed mid-treatment. However, the decreased levels of distress of less resilient participants post-treatment were not associated with the predicted increased levels of QOL ($R^2_{change}=.041$, $F_{change}(1,43)=2.477$, $p=.123$).

Conclusions

Resilience was confirmed as being associated with higher quality of life and lower distress in this sample of patients. Future research should focus on interventions that may enhance resilience in cancer patients and survivors.

51

The Victorian Paediatric Long Term Follow-up Program for survivors of childhood cancer - Model of care

Jessica Fullerton[1]

1. Paediatric Integrated Cancer Services, Paediatric Integrated Cancer Service, Parkville, VIC, Australia

The Paediatric Integrated Cancer Service receives recurrent funding from the Victorian Department of Health and Human Services to facilitate a Long Term Follow-up Program (LTFP) for children and adolescents who have completed their cancer therapy and are entering the survivorship phase of their care.

The LTFP has a strong patient focused approach with an emphasis on wellness and health promotion. The program has been developed based on the experiences of consumers, wide consultation with key stakeholders and service providers and is underpinned by evidence based care. The service model stratifies and triages patients based on diagnosis, treatment and complexity, facilitating shared care as close to home as possible.

The clinical service commenced in 2009 and has continued to grow and evolve. Since commencement, 974 individual patients have attended the program, with 2672 clinic attendances. Patients are seen with a multi-disciplinary approach and are provided with a treatment summary and an individualised roadmap of recommended future clinical follow up. In 2016, the program conducted 111 clinics across the Royal Children's Hospital, Monash Children's Hospital, The Alfred Hospital and the Peter MacCallum Cancer Centre.

The challenge faced by the LTFP is the transition of adolescents into appropriate follow-up services. As of 30th June 2016, 47% (N=484) patients over 17 years of age, have been successfully transferred to community, tertiary and adult health service providers.

This presentation will outline the key components of the Long Term Follow-up program model of care, including the risk stratification model, evolvement of the program, challenges faced and specific clinical outcomes seen.

52

Measuring what matters: An evaluation and outcomes framework for survivorship care programs

Spiridoula Galetakis[1], **Alison Coughlan**[2], **Kathryn Whitfield**[1]

1. Department of Health and Human Services Victoria, Melbourne, VIC, Australia

2. Alison Coughlan, Melbourne, Victoria, Australia

Survivorship care is a complex and evolving area of cancer care that aspires to build capacity for flexible and ongoing cancer care in the community, to meet people's needs. It requires a shift in focus from traditional cancer care delivery, cultural change and system transformation for the development of new models of care in collaboration with primary and community-based services.

The Victorian Cancer Survivorship program (VCSP) Grants Scheme was established in 2011 to spur development of innovative programs and models of care across acute and primary/community care sectors. Prior to the initiation of Phase II of the VCSP grants scheme in 2016, the Department of Health and Human Services Victoria commissioned the development of an evaluation and outcomes framework for cancer survivorship care programs. This framework addresses the key domains of cancer survivorship care to help inform the evaluation requirements of any VCSP funded initiatives.

The framework is designed for use at the project level to inform high quality project design, planning and implementation. It informs an iterative action learning approach to optimise the value and success of the project and helps to provide evidence of the overall impacts achieved by the project for the purposes of business case development and publications.

At the statewide level, the framework will help to generate evidence that will make a contribution to the knowledge base on cancer survivorship, understand the impacts achieved from the government's investment and inform the development of future initiatives.

The presentation will describe the framework's six key domains for evaluation including: model of care design (unique to each project), organisational engagement and leadership, project implementation and evaluation, participation, expected outcomes (at an individual and organisational level) and sustainability and spread.

53

Returning to work was important in a survey of American palliative care patients

Paul Glare[1, 2], Tanya Nikolova[3], Sujata Patil[4], Victoria Blinder[3, 4]

1. Pain Medicine, University of Sydney, Northern Clinical School, St Leonards, NSW, Australia

2. University of Sydney, St Leonards, NSW, Australia

3. Medicine, Memorial Sloan Kettering Cancer Center, New York, NY, USA

4. Biostatistics and Epidemiology, Memorial Sloan Kettering Cancer Center, New York, NY, USA

Aim: To characterize the employment situation of working-age palliative care patients.

Design: Cross-sectional survey of 112 consecutive patients aged 25-64 who were attending a palliative care outpatient clinic at Memorial Sloan Kettering Cancer Center in New York. Respondents completed a 37-item self-report questionnaire covering demographics, clinical status, and work experiences since diagnosis.

Results: The commonest cancer diagnoses were breast, colorectal, gynecologic, and lung. 81% had active disease. 74% were on treatment. 80% recalled being employed at the time of diagnosis, with 65% working full time. At the time of the survey, 44% were employed, 26% working full time. Most participants said work was important, made them feel normal, and helped them feel they were "beating the cancer". Factors associated with being employed included male gender, self-employed, and taking less than three months off work. Respondents with pain and/or other symptoms were significantly less likely to be working. On multivariate analysis, only pain (odds ratio [OR] 8.16, $p<0.001$) and other physical symptoms (OR 5.90, $p=0.012$) predicted current work status; gender (OR 2.07), self-employed (OR 3.07) and current chemotherapy (OR 1.81) were included in the model, but were not statistically significant in this small sample.

Conclusion: Work was an important issue for many of the cancer patients who completed this survey, even though they were needing palliative care. Similar data for Australian patients is needed, as is the development and evaluation of approaches to facilitate ongoing employment for those who wish - or need - to continue working despite their illness.

54

Severe pain, disability, psychological distress and maladaptive coping are common in cancer patients attending Australian pain clinics

Paul Glare[1, 2], Daniel Costa[2], Hilarie Tardiff[3], Michael Nicholas[2]

1. Pain Medicine, University of Sydney, Northern Clinical School, St Leonards, NSW, Australia

2. Pain Management Research Institute, University of Sydney, St Leonards, NSW, Australia

3. Australian Health Services Research Institute , University of Wollongong, Wollongong, NSW, Australia

Aim: to compare the pain characteristics of patients attending Australian pain clinics according to whether they self-report cancer as a comorbidity or not.

Methods: Cross sectional study of questionnaire scores in the national pain clinic registry established under the electronic Persistent Pain Outcomes Collaborative (ePPPOC) initiative. All patients completed the Brief Pain inventory, Depression Anxiety Stress Scale, Pain Self Efficacy Questionnaire, and Pain Catastrophizing Scale.

Results: As of 31 December 2014, some 13,528 patients' questionnaires were available for analysis in the ePPOC registry. 594 recorded cancer as a comorbidity. Another 84 attributed their pain to cancer without selecting cancer as a comorbidity. Together, they account for less than 2% of all cases in the registry. Many cancer patients attributed their pain to other causes. The percentage of patients with questionnaire scores in the severe range, according to whether they report cancer as a comorbidity or not and attributed their pain to cancer or not are shown in the Table below. While these differences are all highly statistically significant, they are not clinically different and indicate cancer patients have similar levels of severe pain, disability, distress and unhelpful thinking as patients with chronic non-malignant pain.

Conclusion: A biopsychosocial approach to pain management is likely to be necessary in patients with a history of cancer, especially when opioids are ineffective or undesirable (e.g. disease free cancer survivors). These findings also suggest that those dealing with pain in cancer survivors should consider using the ePPOC measures to evaluate and guide their pain management.

Cancer comorbidity	yes	yes	no	no
Cancer causing pain	yes	no	yes	no
n	136	413	84	12,615
Pain intensity, severe	25.7%	42.2%	23.2%	35.0%
Pain disability, severe	42.2%	54.8%	36.6%	55.9%
Depression, severe	37.9%	36.6%	35.0%	47.4%
Anxiety, severe	31.8%	55.9%	37.5%	41.6%
pain self-efficacy, poor	34.4%	42.2%	28.0%	43.1%
Catastrophizing, severe	37.7%	54.8%	33.3%	54.1%

55

Ability to adhere to exercise guidelines during stereotactic ablative body radiation therapy for metastasis of renal cell carcinoma in the superior lobe of the left lung: a case study report

Michael C Hartland[1], **Joel T Fuller**[1], **Maximillian J Nelson**[1], **Marcus V Dreosti**[2], **Jonathan D Buckley**[1], **Gaynor Parfitt**[1], **Kade Davison**[1]

1. Alliance for Research in Exercise, Nutrition and Activity (ARENA), School of Health Sciences, Sansom Institute for Health Research, University of South Australia, Adlaide , SA, Australia

2. Adelaide Radiotherapy Centre, Genesis Cancer Care , Adelaide, SA, Australia

Introduction: Lung carcinomas account for 27 % of all cancers deaths, curative treatment is typically open thoracotomy, but recently Stereotactic Ablative Radiotherapy (SABR) has recently been seen as a viable curative treatment option that may not have the same acute debilitating effects on lifestyle. **Purpose:** This study aimed to establish whether a male patient undergoing SABR for an operable lung carcinoma could maintain the American College of Sports Medicine recommended minimum exercise guidelines. **Methods:** The case study reports on a 57 year old male undergoing SABR (48Gy) for a lung carcinoma. The exercise program comprised 5x60 minute aerobic exercise sessions at moderate intensity and 3x45 minute sessions of resistance exercise per week over a 12 week observation period post treatment. Outcome measures including cardiorespiratory fitness, strength and fatigue, as well as psychological measures including depression, anxiety and sleep quality were recorded at baseline and then fortnightly during the observation period. **Results:** The patient achieved a 99% exercise adherence rate with no adverse events. Elevated levels of fatigue were reported from weeks 2-8 and adversely impacted the perception of exercise intensity. Minimal changes were reported in cardiorespiratory fitness, strength, depression, anxiety and sleep quality. **Conclusion:** This is the first reported clinical case of the safety and efficacy of maintaining an exercise regime during SABR for a lung carcinoma. The evidence suggests that exercise participation meeting exercise guidelines may be feasible for patients undergoing this treatment. Future research, utilising controlled study designs, is necessary to determine whether this result is representative of a broader sample of patients.

56

Developing a sustainable model of care for cancer survivors

Genevieve Johnston[1], **Wanda S Stelmach**[1], **Hugh Burch**[1, 2], **Claire Consiglio**[1], **Cheryl Murray**[1]

1. Northern Health, Epping, VIC, Australia

2. NEMICS, Heidelberg, VIC, Australia

Background: Due to improvement in treatment options, the number of cancer survivors is increasing. All survivors should receive a Survivorship Care Plan (SCP) to guide holistic care of chronic treatment morbidities, meet information needs and assist transition to primary healthcare. In Australia, SCPs are not routinely implemented with barriers including: limited advocacy from clinical leaders, limited coordination between acute and primary healthcare practitioners, and a lack of resources.

Aim: To investigate the sustainable implantation of SCPs across Victorian health services and to determine the potential decrease in reliance on outpatient appointments for the breast team at Northern Health (NH).

Method: This research had two phases. Benchmarking was undertaken through consultation with with five Victorian co-ordinators that have introduced survivorship models of care. Modelling was then undertaken to determine the number of NH breast cancer patients eligible for GP follow up via a Shared Care model, and the potential decrease in reliance on NH outpatient appointments.

Results: Benchmarking indicated that the completion of SCPs with patients is resource intensive. This is a significant barrier to sustainable implementation. Subsequently, survivorship models have been implemented in tumour streams with embedded dedicated nurse co-ordinators. The mean annual number of people diagnosed with breast cancer at Northern Health between 2010-2015 was 79.2 (±9.85). Of these, 62% met the criteria for Shared Care and the mean annual number of people eligible was 48.67(±5.51). If eligible patients were to have every second appointment with their GP, whilst still maintaining Cancer Australia's recommendations for review, a shared care model could save 1715 acute outpatient appointments over a 5 year period.

Conclusions: Shared Care can decrease reliance on acute outpatient appointments, improve patient flow and potentially decrease waiting time for newly diagnosed breast patients. Health services require dedicated staffing to ensure care plans are sustainably implemented across tumour streams.

1. Institute of Medicine and National Research Council of the National Academies, From Cancer Patient to Cancer Survivor: Lost in Transition. 2006, Washington, D.C.: The National Academies Press.
2. Mayer, D., et al., American Society of Clinical Oncology clinical expert statement on cancer survivorship care planning. Journal of Oncology Practice, 2014.
3. Birken, S., et al., Determinants of Survivorship Care Plan Use in US Cancer Programs. Journal of Cancer Education, 2014. 29(4): p. 720-7.
4. Grunfield, E., et al., Randomized Trial of Long-Term Follow-Up for Early-Stage Breast Cancer: A Comparison of Family Physician Versus Specialist Care. Journal of CLinical Oncology, 2006. 24: p. 848-55.
5. Cancer Australia. Shared follow-up care. 2013 9.2.15 [cited 2016]; Available from: https://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/shared-care-information-women.

57

Survivorship in a Regional Setting

Michelle Judd[1]

1. Hume RICS, Shepparton, VIC, Australia

Survivorship is becoming recognized as a distinct phase in the cancer care continuum. The Optimal Care Pathways explain that "international research shows that there is an important need to focus on helping cancer survivors cope with life beyond their acute treatment." (Cancer Council, 2015) The Hume Regional Integrated Cancer Service (Hume RICS) implemented a survivorship program for cancer survivors, the Hume Survivorship Service (HSS) in two regional settings (West and Border East Hume) to assess unmet needs and ensure patients receive follow-up care according to their needs to reduce the physiological and psychological impact of cancer.

Following completion of active treatment, patients aged 18 years and over were referred to the HSS for assessment and referral to a range of follow-up services that assess medical and psychosocial concerns. The outcome of many of these referrals was to the

Wellness and Life after Cancer Program (WALAC). This program is underpinned by a focus on health literacy, patient empowerment and health prevention utilising a chronic disease management approach, in conjunction with primary care and community health providers.

The aim of the program is to cater to the needs of cancer survivors in the Hume region by facilitating regular cancer focused information sessions and providing expertly coordinated care to people who have ongoing health needs after completion of treatment . With the support of Cancer Council Victoria (CCV), the HSS piloted the first WALAC in Shepparton in November 2015. Following on from this first program, the HSS worked closely with CCV to evaluate and improve the content delivered within WALAC.

58

Long term outcomes and risk factors for chemotherapy induced peripheral neuropathy in childhood cancer survivors

Tejaswi Kandula[1, 2]**, Michelle A Farrar**[1, 2]**, Matthew C Kiernan**[3]**, David Mizrahi**[4]**, Kate Carey**[2]**, Arun V Krishnan**[5]**, Susanna B Park**[3, 5]**, Richard J Cohn**[4]

1. Sydney Children's Hospital, Randwick, Sydney, NSW, Australia

2. School of Women's and Children's Health, University of New South Wales, Sydney, NSW, Australia

3. Brain and Mind Centre, University of Sydney, Sydney, NSW, Australia

4. Kids Cancer Centre, Sydney Children's Hospital, Sydney, NSW, Australia

5. Prince of Wales Clinical School, University of New South Wales, Sydney, NSW, Australia

Background: Chemotherapy induced peripheral neuropathy (CIPN) may be an important cause of morbidity in childhood cancer survivors (CCS), contributing to reduced physical function and restricted participation in day-to-day activities. This study aimed to evaluate the prevalence and impact of CIPN in long term CCS.

Methods: Comprehensive neurotoxicity assessments were undertaken in CCS who completed platinum or vinca alkaloid based chemotherapy >5 years ago, comprising of clinical, functional, quality of life and neurophysiological parameters including conventional nerve conduction studies and novel nerve excitability studies.

Results: Neurotoxicity assessments were performed on 110 participants aged 7-47 years, who received chemotherapy at a mean age of 5.8±0.4yrs and completed treatment 11.2±0.7yrs ago. 33% of patients demonstrated clinical and/or neurophysiological evidence of peripheral neuropathy. Overall, CCS demonstrated reduction in sensory amplitudes compared to age-matched controls (Mean difference -6.3μV; 95%CI -9.6, -3.0μV; p=0.0003), suggesting an impact on axonal reserve. Participants treated with platinum agents (p=0.008) or dual neurotoxic chemotherapy were most affected (p=0.01). There were persistent abnormalities in functional excitability properties of sensory nerves in participants with prior cisplatin treatment (p<0.05). Clinical functional parameters of manual dexterity (44.5th percentile, 95%CI 36.1, 52.9%), balance (49th percentile, 95%CI 38.9, 59%) and co-ordination (55.9th percentile, 95%CI 46.9,65%) were relatively preserved compared to the normal population.

Conclusion: CIPN produces significant long term morbidity in CCS. Clinical and neurophysiological abnormalities in CCS are consistent with global axonal loss, which may predispose to further age-related degenerative change. Exposure to platinum or dual neurotoxic chemotherapy are risk factors for long term neuropathy. Relative preservation of clinical function suggests a window of opportunity for physical therapy which may preserve long term function.

59

"Engage Community Forums" An initiative developed and driven by GI Cancer survivors and carers

Dan Kent[1, 2]

1. AGTIG, Avoca, QLD, Australia

2. AGITG?GICI Consumer Advisory Panel, Avoca, QLD, Australia

Introduction:

GI Cancer survivor and carer members of the GICI/AGITG CAP have been the developers and drivers of a series of Forums to raise community awareness about gastro-intestinal cancers, treatments, clinical trials, support services and survivorship.

Method:

Engage Community Forums have been held in all Australian capital cities, excluding Darwin, and in regional and larger suburban centres of Newcastle, Gawler, Albury, Orange, Bundaberg, Epping, Hawthorne and Mt Pritchard in the period 2013-2016.

Engage Forum programs include expert clinician speakers on the aspects of GI Cancer - the Big Picture, Latest Advancements in Research and Treatments, allied health professionals on Quality of Life aspects, together with a personal 'survivorship' experience story. Forum programs have been tailored to meet any indentified local needs. Question Time followed by refreshments and around table displays by organisations such as Colostomy Association, Cancer Council, Look Good Feel Better. These organisations provided an additional source of information/support for attendees.

GICI/AGITG CAP members guided the development of the program, selection of speakers and relevant local contacts, groups and organisations. GICI/AGITG staff provided the support necessary to implement the Forums.

Results:

Over 1200 people attended in total, and highly positive feedback was obtained.

Early successful capital city Forums in 2013 encouraged the GICI/AGITG CAP to suggest holding forums in rural and regional areas. Forums in regional areas were enabled by a Cancer Australia *Supporting people with cancer* Grant during 2014-16.

Conclusions:

Engage Community Forums are an initiative established by survivors and carers to raise awareness of gastro-intestinal cancers and encourage participation in clinical trials. This collaboration between survivors, carers, GICI/AGITG, cancer clinicians and local communities is a novel model that is helping address regional inequalities in cancer outcomes, improve screening numbers and increase clinical trial participation.

60

Living an adventurous life with Lymphoedema: One patient's journey to acceptance and Management

Ruth V Klee[1]

1. Lymphoedema Support Group of South Australia (LSGSA), Port Augusta, SOUTH AUSTRALIA, Australia

POSTER abstract

Being an overseas trained professional Social Worker in the Australian health service, then becoming “the patient” with a Breast Cancer diagnosis has been a challenging journey since March 2013. The acute cancer treatment pathway vs. the more chronic nature of the Lymphoedema condition which followed was more overwhelming to consider as it is ongoing as compared to the treatment for cancer which had a finishing point. In this presentation, exploration of the acceptance of Lymphoedema found through information, education and treatment strategies will be shown and celebrated. The link between my personal journey and how I brought these lessons to my professional practice with other patients will also be considered. Instilling hope and the fact that life goes on are important messages professionals need to provide to patients to promote acceptance.

Poster References:

2 Australian Association of Social Workers website (www.aasw.asn.au)

3 Social Work Intervention Research with Adult Cancer Patients: A Literature Review and Reflection on Knowledge-Building for Practice, R. Pocket; M. Dzidowska; K. Hobbs, Social Work in Health Care 54:582-614, 2015

4 Living a Health Life with Chronic Conditions: Self-Management, K. Lorig et al, Third Edition

61

The self-coach BREATHE approach to optimise quality of life after cancer

Tricia LaBella[1], **Claudine Burgess**[1]

1. Real Time Enhancements, Highbury, SOUTH AUSTRALIA, Australia

A cancer diagnosis brought 2 professional women together to begin a journey to explore how wellbeing practices could be encouraged at the point of a cancer diagnosis.

When people are diagnosed with cancer, while there is a strong emphasis on the treatment ahead, is there also a place for wellbeing to be promoted as a primary support strategy during this time?

If so, given the differences in demographics, cancer situation and personal factors and values, how can this be available to everyone?

With self management emerging as a recognised sustainable formula, we developed a ‘self coach’ approach that fits the key factors identified for an effective design including easy, attractive, and social and a timely approach[1].

The approach, delivered through a simple, colourful, easy to follow and memorable acronym **BREATHE (Breathe, Regroup, Empower, Action, Treatment, Healing, Escape)** is designed for participants to create their own achievable, sustainable wellbeing choices that fit within their current life context.

To date we’ve developed 2 self coach cancer programs that are soon to be launched.

1. An online program delivered via an interactive ‘moodle’ with self care, wellbeing practices, personal management as key themes in an inclusive, non prescriptive and flexible platform engaged anytime, anywhere
2. A 6 week ‘Walk and Talk’ Moving through cancer group program to empower people to exercise safely and with confidence through a cancer experience

In conclusion, is there a place for this ‘self coach’ approach to be researched as an upfront strategy alongside other services to promote wellbeing for cancer recovery?

1. Supporting self-management- A guide to enabling behaviour change for health and wellbeing using person- and community-centred approaches (2016) http://www.nesta.org.uk/sites/default/files/rtv-supporting-self-management.pdf (accessed 30 Sep 2016)

62

Life after cancer treatment - a peer support group pilot study

Eleanor Law[1], **Andreea Ardeleanu**[1]

1. ACT Health, Phillip, ACT, Australia

Aims

The Life After Cancer Treatment Group pilot study was a survivorship therapeutic support group targeted at people with cancer at primary diagnosis stage, after completion of treatment. Group numbers were kept under 10 to facilitate participation. The three main aims of this group were:

1. to provide a safe environment for exploring issues characteristic of the survivorship phase and psychosocial education within an Acceptance and Commitment Therapy (ACT) model,
2. to provide participants with an opportunity to experience mindfulness practices, in the context of the ACT model, and
3. to provide an opportunity for peer networking within a shared experience framework.

Method

The group included six meetings, each focussed on a different theme. Ten participants enrolled in the group; two withdrew (N= 8). The group was conducted within an ACT framework, with a focus on demonstrating and practicing mindfulness. Themes covered included stress/anxiety management, living with uncertainty, myths/expectations associated with cancer treatment/recovery/survivorship, body image, and long term self-care moving into the survivorship phase. Pre- and post-program questionnaires were completed with the opportunity to provide qualitative feedback.

Results

Post-program survey data demonstrated that participants experienced positive outcomes from attending the group. In addition, qualitative comments confirmed the psychosocial skills acquired included positive outcomes such as feeling ‘calmer’; ‘more connected’; ‘normal’; ‘more in control’ and ‘looking forward to the future’. Feedback on the peer network component was positive, indicating long-term connections were established.

Conclusions

The Life After Cancer Treatment Group pilot study assisted participants positively in their cancer survivorship journey. The data and feedback confirmed the importance of peer support as a strategy in the cancer survivorship process. The program will be repeated with greater integration of strategies to expand the collection of data to further elucidate the importance of peer network support within a therapeutic support group format.

63

Improving brain tumour care online

Heidi McAlpine[1, 2], **Magdalena Sejka**[2], **Lynette Joubert**[3], **Fernando Martin-Sanchez**[1], **Katharine J Drummond**[2, 4]

1. Health and Biomedical Informatics Centre, University of Melbourne, Parkville, Australia

2. Department of Neurosurgery, The Royal Melbourne Hospital, Parkville, Australia

3. Department of Social Work, University of Melbourne, Parkville, Australia

4. Department of Surgery, Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne, Parkville, Australia

Aims: Online interventions for brain tumour patients have the potential to transgress geographic, physical and psychological barriers to healthcare, and to facilitate treatment, support and education for patients within convenient timeframes and their own environment. Our published literature review examining online interventions for cancer patients found current interventions demonstrated mixed efficacy when rigorously evaluated. The current study is a needs assessment of online resources for brain tumour patients, undertaken with a view to creating an online therapeutic community. The survey considers social media use, patient demographics and quality of life (FACT-B).

Methods: The survey has been created using SurveyMonkey software administered on iPads. Participants include those >18 years of age with a diagnosis of primary brain tumour, attending the Royal Melbourne Hospital Neuro-oncology clinic.

Results: 201 patients with primary brain tumours were surveyed between 2014 and 2016. 55.7% were female and 61.7% were aged greater than 40 years. 85.9% of patients used the Internet and of those 71% had looked up information about brain tumours. Patients used a number of social media platforms for information, communication or interaction related to their brain tumour. Social networking sites (SNS) were most frequently used (32.8%), followed by wikis (28.1%) and blogs (13.2%). 69.2% of those using social media found SNS valuable for information, communication or interaction related to their brain tumour. Furthermore, patients reported many determinants of QoL to be positively affected by use of SNS, reporting that SNS helped their ability to take in new information, ability to sleep, ability to enjoy life and ability to participate in social activities.

Conclusions: Results suggest social media plays a powerful role in self-management for patients with brain tumours. This information emphasizes the importance of social media for patients, and will help guide the creation of a specialized platform to help these patients with self-management.

64

Enriching Survivorship

Lauren McClean[1], **Jill Mills**[1], **Annie Miller**[1]

1. Cancer Council NSW, Kings Cross, NSW, Australia

Background

ENRICHing Survivorship is a holistic 8-week face to face program that aims to facilitate health behaviour change and improve emotional wellbeing of cancer survivors and carers. The Program is made up of: Nutrition and Exercise (6 sessions); Yoga/Mindfulness (1 session); Peer Support (1 session).

Method and sample

At the conclusion of the Program, participants were asked to complete a survey that assessed: their level of knowledge, understanding, skill and confidence (retrospective pre/post questions), behaviour changes, self-reported changes in general health, fatigue, sleep patterns, and mood; and basic demographics.

Most participants were female (78%); had a previous cancer diagnosis (78%); 41% were aged 51-60. Nearly three-quarters of all participants had attended between 5 and 8 sessions.

Results[*]

***Nutrition and exercise*:** Participants gained a greater understanding of the importance of a healthy diet and exercise*; increased their knowledge regarding a balanced diet and exercises they could perform to improve their health*; felt more confident to include these aspects into their lives*; and gained skills around the selection of healthy options and exercise safety*.

Around 70% of participants noted that they were now including healthy foods into their diet more often; and had increased the amount of exercise they did weekly.

***Peer support*:** Participants found it of benefit to be around others who were in a similar situation, they gained knowledge about issues facing survivors*, and had their experience normalised through recognising that others share similar concerns*.

Yoga/mindfulness: Raised awareness of the importance of the practice, and gave people the skill, knowledge and confidence to make it part of their life*.

Overall health and well-being: Self-reported improvements were noted for general health, with 84% of participants indicating they felt somewhat or much better; 65% noted improvements in their level of fatigue; 67% had better sleeping habits; 80% noted an improvement in feelings of worry and anxiety; and 85% noted an improvement in their feelings of sadness and depression.

Conclusions

Bringing together a combination of practical survivorship support programs into one holistic program provides significant benefit to cancer survivors and their carers.

[*] *Notes statistically significant difference in pre-and-post scores, as measured by paired sample t-test, p<.001*

65

Webinars providing education and empowerment for cancer survivors and health professionals

Jill Mills[1], **Annie Miller**[1]

1. Cancer Council NSW, Kings Cross, NSW, Australia

Introduction:

Webinars provide online delivery of evidence based information specifically developed for Cancer Survivors, families and their carers. They may be viewed on any digital device and are accessible 24/7, regardless of location. They educate Health Professionals regarding survivorship issues to help support their patients after treatment.

Objectives:

To provide evidence based information and strategies for cancer survivors in an accessible, cost effective and sustainable manner.

Methods:

Webinars are delivered live online, with the webinar recording and follow-up resources provided by email and accessible online, at any time, on any digital device. Cancer survivors tell their story in relation to the topic being addressed, providing an important factor of *'normalising'* the cancer experience. Eminent health professionals deliver current evidence based information addressing the highest unmet needs of cancer survivors.

Results:

Twenty webinars have been conducted since April 2014, resulting in excess of 6,000 registrations. Nearly 50% of all people who registered have watched the live or the recorded webinar, with a cost of $12.35 per head. Of those who registered 36% were cancer survivors, 10% family and/or carers, 13% in treatment, 26% Health Professionals and 15% opted not to answer. 43% completed the exit survey after the live webinars. The survey found that 90% of people increased their knowledge, 89% were provided with strategies and 84% were confident they could apply those strategies.

Conclusions:

Webinars provide a convenient forum to engage and empower cancer survivors regardless of their personal circumstances to obtain new information. Further research is required to assess the noted intention of participants to implement lifestyle strategies and the translation of this intent into behavioural change, or further help seeking. Also, to investigate if Health Professionals are referring clients to the webinar resources.

66

Physical activity in survivors of childhood cancer: results from a long-term follow-up study, systematic review and meta-analysis

David Mizrahi[1, 2], **Joanna Fardell**[2, 3], **David Simar**[1], **Claire Wakefield**[2, 3], **Briana Clifford**[1], **Qishan Lim**[3], **Veronica Quinn**[2, 3], **Jordana McLoone**[2, 3], **Frank Alvaro**[4], **Tom Walwyn**[5], **Richard Cohn**[2, 3]

1. School of Medical Sciences, Faculty of Medicine, University of New South Wales, Sydney, NSW, Australia

2. Behavioural Sciences Unit proudly supported by the Kids with Cancer Foundation, Kids Cancer Centre, Sydney Children's Hospital, Sydney, NSW, Australia

3. Discipline of Paediatrics, School of Women's and Children's Health, Faculty of Medicine, University of New South Wales, Sydney, NSW, Australia

4. Department of Paediatric Oncology, John Hunter Children's Hospital, Newcastle, NSW, Australia

5. Department of Oncology and Haematology, Princess Margaret Hospital for Children, Perth, WA, Australia

Aims: This study aimed to assess physical activity levels in childhood cancer survivors (CCS), compare these to recommended guidelines, and investigated the feasibility of distance-delivered physical activity interventions amongst CCS.

Methods: CCS (aged≥16) and parents (survivors aged<16) from 11 hospitals in Australia and New Zealand participated in this study. Participants self-reported their moderate-vigorous physical activity (MVPA). This was compared to American Cancer Society's physical activity guidelines (150 minutes/week for adults, 300 minutes/week for children). A systematic review and meta-analysis were conducted to determine the feasibility (adherence, retention and recruitment rates) and effect of distance-delivered interventions on physical activity levels, physical and psychological function after intensive treatment.

Results: 329 CCS (mean age=27.7±7.2years, 20.3±8.3years since diagnosis) and 254 parents of CCS (mean age=14.0±2.8years, 10.9±2.9years since diagnosis) participated. Adult CCS reported mean MVPA of 115.9±129.8 minutes/week and children had MVPA of 231.3±227.8 minutes/week, which was in both cases lower than recommended guidelines (both $p<0.001$). Only 31.3% of adults and 29.1% of children achieved recommended MVPA guidelines. Our systematic review included 13 studies (n=270 participants), while 5 (n=115 participants) were included in the meta-analysis. Distance-delivered physical activity interventions were feasible in CCS (mean recruitment rate=64%, retention rate=85%, adherence rate=88%), and significantly increased physical activity levels from baseline to post intervention ($p=0.019$). Participation in physical activity interventions displayed a positive effect on physical function ($p=0.002$) and psychological outcomes ($p=0.001$).

Conclusions: Over two-thirds of child and adult CCS are not achieving recommended levels of physical activity. Strategies including education and earlier monitoring are needed to increase physical activity levels and lower the risk of cardiovascular and metabolic co-morbidity. CCS may experience barriers including fatigue, access to facilities or lack of guidance, but our investigation into distance-delivered interventions to increase physical activity levels suggests that such interventions could represent a viable option to tackle this important issue.

67

Principles of Cancer Survivorship – guiding a national approach to policy and health services planning

Caroline Nehill[1], **Christine Giles**[1], **Helen Zorbas**

1. Cancer Australia, Strawberry Hills, NSW, Australia

Introduction

In 2016, it is estimated that there are 1.1 million people living in Australia who have been diagnosed with cancer.[i] With an increasing number of people living longer with cancer and other chronic diseases, there is a need to address the long-term health and wellbeing of people affected by cancer.

Method

Cancer Australia undertook a top-line literature search for high level evidence of published principles of survivorship in cancer. The extracted sources were considered with reference to: principles or elements of cancer survivorship, and definitions of survivorship.

Draft Principles were developed from the key areas and tested against four domains:

- Improving wellbeing of people affected by Cancer
- Informed by the latest evidence on cancer survivorship
- National application across cancer types and health settings
- Opportunity to guide improvements in cancer across the continuum-of-care.

A roundtable discussion with key stakeholders in survivorship care including consumer representation was convened to consider the Principles as a framework to guide policy, planning and health system responses to survivorship.

Results

There was broad consensus for the importance of the Principles to provide high-level guidance to enable all levels of government and health service planners to develop future policy, actions and strategies to improve outcomes for people who have had a diagnosis of cancer.

Cancer Australia's *Principles of cancer survivorship*:

- Consumer involvement in patient-centred-care
- Support for living well
- Evidence-based pathways
- Integration and coordination-of-care
- Data driven improvements and investment in research improvements

The Principles are underpinned by elements which support personalised care, opportunities for supported self-management, an emphasis on recognising and incorporating patient experiences, and a focus on recovery, health and wellbeing during and after cancer treatment.

Conclusions

A multifaceted strategy will guide national promotion of the *Cancer Australia Principles of Cancer Survivorship* as a framework to guide policy, planning and health system responses to cancer survivorship.

1. Cancer Council Australia. Australian cancer prevalence exceeds one million. Cancer Forum. 2016;40(2)169

68

Development of comorbidities in hormone-dependent breast cancer survivors treated with endocrine therapy: an Australian population-based analysis

Huah Shin Ng[1], **David Roder**[1], **Bogda Koczwara**[2], **Agnes Vitry**[1]

1. University of South Australia, Adelaide, SA, Australia

2. Flinders Centre for Innovation in Cancer, Flinders Medical Centre, Flinders University, Bedford Park, SA, Australia

Aim: Despite growing recognition of the impact of comorbidities on the care and health outcomes of cancer survivors, there is little data on comorbidity available in the Australian context which may inform the development of better policy and practice. This study aims to assess the development of comorbidities among Australian women treated with endocrine therapy for hormone-dependent breast cancer.

Methods: Prescription claims data from the Australian Government's Pharmaceutical Benefit Scheme 10% sample were utilised. Comparisons were made between women who initiated endocrine therapy between year 2004 and 2011 and an age- and sex-matched control group (at 1:5 ratio) without any dispensing record of anti-neoplastic agents during the study period. Prescription claims data were used to identify comorbidities and classified with the Rx-Risk-V model. A Cox regression model was used to evaluate the development of specific comorbidities over time and was adjusted for number of baseline comorbidities.

Results: Gastric acid disorders, heart failure/hypertension and dyslipidemia were the top three most prevalent comorbidities among breast cancer survivors prior to the initiation of endocrine therapy. The hazard ratio (HR) for developing depression (HR 1.32, 95% CI 1.20-1.47), osteoporosis (HR 1.26, 95% CI 1.11-1.42), cardiovascular disease (HR 1.19, 95% CI 1.07-1.33) and diabetes mellitus (HR 1.25, 95% CI 1.05-1.49) were higher among breast cancer survivors compared to women without cancer. The HR for developing dyslipidemia (HR 0.87, 0.78-0.98) was lower among breast cancer survivors. There was no significant differences between the two groups for reactive airway disease and gastric acid disorders.

Conclusion: Comorbidity is more prevalent among breast cancer survivors than women without cancer. Our results further support the need to develop appropriate models of care to address multiple chronic conditions experienced by breast cancer survivors.

69

A patient survey to develop follow up care for 15 -25 year olds with a cancer diagnosis, 1-5 years after the completion of cancer treatment. 'Will establishing a multidisiciplinary psychosocial clinic improve outcomes, provision and coordination of this age group?'

Cath O'Dwyer[1], Fiona Edgar [1], Antoinette Anazodo[1]

1. Sydney Youth Cancer Services, The Prince of Wales Hospital , Randwick , NSW, Australia

Aim

Cancer care should not end when treatment ends. The literature shows that follow up cancer care for adolescents and young adults (AYA) 1-5 years off treatment differs across adult and paediatric hospital settings. Factors that affect the care include resources, coordination of care, historical practise and communication between multi-disciplinary teams[1,2].

The aim of the survey was to review a cohort of AYA's and examine their experience of follow up care from the end of cancer treatment up to 5 years. It is anticipated that this will show a gap in services and that there is an absence of a coordinated comprehensive approach and individualised provision of care. Establishing a multidisciplinary psychosocial clinic aims to optimise AYA wellbeing and improve overall survivorship outcomes.

Method

A literature search was undertaken to determine current practise and to identify what the essential features of high quality follow up cancer care should encompass[1, 2.]

A Likert scale type survey was developed (20 questions) to gather information about the actual experience of follow up care. This included surveying twenty AYA's who have completed cancer treatment and are attending medical follow up appointments. Ten aged between 15-18 and ten aged 18-25 to capture patients in different hospital settings (paediatric and adult).

Conclusions

Once all the surveys are completed and analysed, it is anticipated the results of the research will demonstrate there is a need for a more co-ordinated approach to follow up cancer care. The literature provides us with valuable evidence to show that this need can be met through the establishment of nurse led clinics. Also that there is a positive impact and greater satisfaction for AYA to attend nurse led co-ordinated clinics for their follow up cancer care.[1, 2.]

1. Grant M, Economou D, Ferrell B. Oncology Nurse Participation in Survivorship Care. Clinical journal of oncology nursing. 2010;14(6):709-715. doi:10.1188/10.CJON.709-715. Gates P, Krishnasamy M. Nurse-Led Survivorship Care. Cancer Forum. 2009: 33 (3).

70

Love, Faith and Hope - A secondary analysis of prostate cancer survivors and their partners

Peter K O'Shaughnessy[1], Thomas A Laws[2], Adrian J Esterman[1]

1. School of Nursing and Midwifery, Division of Health Sciences, University of South Australia, Adelaide, SA, Australia

2. School of Nursing and Midwifery, Keele University, Keele, Staffordshire, UK

Aims

This study aimed to explore the impact of emotions such as love, hope and faith on prostate cancer survivors and their partners. Men's experience of recovery from the treatment for prostate cancer has been extensively researched, with reports highlighting the side effects of erectile dysfunction, incontinence as well as the fear of cancer recurrence. However, the stories of men who develop psychosocial gains and emotional strength are rarely recognised.

Methods

A secondary thematic analysis of data collected by the researchers in a series of separate but related qualitative studies was conducted to explore the emotional impact of prostate cancer survivorship.

Results

In this study it was found emotive concepts of love, hope and faith were important cornerstones in prostate cancer survivor's psycho-social well-being. Analysis revealed men's understanding of love, hope and faith changed as they progressed from diagnosis and initial treatment, into long term survivorship.

Men with partners were free and effusive in describing the significance of the love, care and compassion provided by their partners and families. These emotions were linked to men's decisions making regarding treatment, and resilience with negative treatment outcomes. Participants in this study identified inner peace, hope and optimism as being an important part of their health related quality of life. Faith was interpreted as a personal journey that linked to sub-themes such as space (physical locations), their relationships, and as a means of re-establishing hope.

Conclusions

The challenge of surviving prostate cancer was not always a negative experience for men in this study. Survivorship could be a growing and healing process that allowed men to find peace and contentment that brought couples closer together. Asking questions about the love, hope and faith in men's lives will go some way to providing a more comprehensive understanding of the supportive care needs of these men.

71

Clinical Innovations: Lymphoedema management

Neil B Piller[1], Malou C van Zanten[1]

1. Lymphoedema Clinical Research Unit, Flinders University, Adelaide, SA, Australia

Literature Review:

Lymphoedema is a chronic condition associated with cancer treatment. It's characterised by the accumulation of protein rich fluids and high inflammatory mediators in the tissues.

Breast cancer related lymphoedema occurs in 21% of breast cancer patients. The arm and/or breast and torso are affected. Gynaecological cancer related leg lymphoedema occurs in between 25-47% of patients while between 9-29% of melanoma survivors develop it.

Early detection of sub-clinical changes can reduce the risk of its clinical development and progression. This is most accurate if pre- and post-surgical measurements are taken as well as, education about risk factors that can improve self-efficacy and coping ability. Unfortunately, there are inconsistent early detection protocols which lead to needless fear or unnecessary risk.

There are recommendations to prevent lymphoedema onset and to slow or stop its progression. These include those relating to injections, blood draws or blood pressure measurements on the affected/at risk limb. Although this is reasonable advice there is limited supporting evidence. A study of over 3,000 patients found no association between insult to the affected/at risk arm in patients who had blood drawn, injection in the affected/at-risk arm, long flights, or blood pressure measures. There was a strong association with infection and increased body weight. However, if there is a possible risk then it’s imperative to avoid it or minimise it. Getting the balance right between risk and fear of developing lymphoedema is hard but education of the patient can go a long way. But, in addition, if we want to improve quality of life in cancer survivors; we need to develop a better action plan encompassing lymphoedema awareness, diagnosis, education, support and management.

72

Promoting the role of primary care in cancer survivorship

Amanda Piper[1], **Judy Evans**[2], **Liz Simkiss**[3], **Linda Nolte**[4], **Georgina Wiley**[1], **Kathryn Whitfield**[3], **Michael Jefford**[1, 6, 5]

1. Australian Cancer Survivorship Centre, A Richard Pratt legacy, Peter MacCallum Cancer Centre, Melbourne, Victoria

2. Peter MacCallum Cancer Centre, Melbourne, VIC, Australia

3. Cancer Strategy and Development, Department of Health and Human Services, Melbourne, VIC, Australia

4. Advanced Care Planning Department, Austin Hospital, Heidelberg, Victoria, Australia

5. Department of Cancer Experiences Research, Peter MacCallum Cancer Centre, Melbourne, Victoria

6. Sir Peter MacCallum Department of Oncology, Peter MacCallum Cancer Centre, Melbourne, Victoria

Aims: There is growing recognition of the importance of primary care in cancer survivorship care (CSC). From the 2015 General Practice Clinical Placement Pilot Program, (1) general practitioners (GPs) noted limited opportunity to describe their role in CSC, and (2) most learning was from hospital specialists to generalists, rather than bidirectional. To support an expanded GP placement program in survivorship, videos were developed to illustrate the role of GPs in CSC. The goal was to improve understanding of the role of primary care in CSC, with a particular emphasis on shared care.

Methods: Video content included messages from specialists, survivors and GPs describing key components of primary care in CSC. Messages were evidence-based and developed with reference to published literature, Australian practice and qualitative interviews. The final videos were evaluated for self-rated knowledge and confidence changes, and relevance, through an online survey.

Results: Interviews with cancer survivors (n=4) and medical and nursing professionals from hospital (n=4) and primary care services (n=6) revealed key themes for the videos: (i) shared care provides holistic and coordinated care; (ii) shared care requires quality information sharing and clear roles and responsibilities; (iii) patients accept and value shared care. A suite of videos were developed for 3 audiences: survivors, hospital specialists and primary care. Preliminary evaluation (16 responses: 10 primary care professionals, 3 hospital health professionals, 2 survivors, 1 unknown) showed the majority: agreed/strongly agreed they ‘had a better understanding of shared care’ (n=12/16, 75%); agreed/strongly agreed the video ‘increased their confidence in the role of GPs in cancer care’ (n=12/16, 75%); agreed/strongly agreed ‘the video was relevant to them’ (n=12/14, 86%).

Conclusions: The videos appear to enhance viewers’ knowledge and confidence regarding the role of GPs in CSC. They should be included with other strategies to promote the role of primary care in CSC.

73

Engagement of general practice in cancer survivorship

Meron E Pitcher[1], **Bianca Bell**[1], **Leanne Storer**[1], **Sally Greenberg**[1]

1. Western Health, Footscray, VIC, Australia

General practice plays a pivotal role in cancer survivorship. With increasing numbers of long term survivors, associated comorbidities and late effects of treatment are appropriately managed in a Community setting. The great diversity of general practice and the perception of cancer as complex and requiring tertiary care has meant that engagement between cancer services and community practice has been patchy at best.

The Western Health breast unit has used a number of strategies to establish and improve communication between these teams to enable joint survivorship care.

These include:

notification by one page fax at time of commencement of chemotherapy, including common side effects and rapid re-referral paths

development of survivorship care plans as part of shared care- and the agreement of the appropriateness of an "opt out" model

Development of an advanced breast cancer pathway with improvements in timing and provision of information to GPs.

hospital GP liaison officer promoting survivorship care in newsletters, and with primary health care networks

regular education sessions targeting practice nurses as well as general practitioners, showcasing multidisciplinary care and highlighting long term issues. Including a consumer has been particularly powerful in reinforcing the role of general practice.

practice nurse and GP placement in nurse led survivorship clinics

developong a pilot program of a GP representative at MDT to allow timely 2 way communication.

Change is reliant on excellent communication and development of mutual trust. It is inevitably slow but critical to enable better care for our patients.

74

Does multidisciplinary outpatient oncology rehabilitation meet the needs of cancer survivors? A retrospective study

Kathryn Rorke[1], **Michael Leach**[2]

1. Allied Health, Saint John of God (SJOG) Bendigo Hospital , Bendigo, VIC, Australia

2. Loddon Mallee Integrated Cancer Service (LMICS), Bendigo, VIC, Australia

Aims:

Saint John of God (SJOG) Bendigo Hospital runs an individualised group outpatient oncology rehabilitation program that combines exercise and education from multiple allied health disciplines to treat patients diagnosed with cancers of various types and stages, during or after treatment. The program was designed to address the short- and long-term side effects of cancer treatments. This study aimed to assess whether cancer survivors' quality of life and fitness outcomes changed following completion of the SJOG oncology rehabilitation program.

Methods:

This study retrospectively reviewed those patients discharged from the SJOG oncology rehabilitation program between May 2014 and June 2016 who completed pre- and post-program assessments (n = 58). Eligible patients' discharge letters were examined. Changes in physical, functional and psychosocial outcomes from before to after the program were assessed using the paired samples t-test or the Wilcoxon signed-rank test. For each patient outcome measure, the choice of test was guided by whether the difference in pre-and post-program scores was normally distributed. P-values < 0.05 were considered significant. A descriptive analysis of the program model was conducted to understand its impact and identify if it met the needs of cancer survivors.

Results:

Demographically, 64% of the patients were aged 65 years or over, 67% were women and the most common cancer diagnoses were gastrointestinal (33%), breast (29%) and haematological (17%). From before to after the program, there were significant improvements in all five outcomes. This included significant improvements in FACT-G (Functional Assessment of Cancer Therapy – General) quality of life score (n = 57, mean improvement = 9 points, p[paired samples t-test] < 0.001) and distance walked in 6 minutes (n = 55, mean improvement = 128 metres, p[paired samples t-test] < 0.001).

Conclusions:

Cancer survivors' physical, functional and psychosocial health outcomes improved significantly following completion of the SJOG oncology rehabilitation program.

75

Five years of GP shared care for cancer survivors with complex needs: what have we learned?

Josie Samers[1], **Goroncy N**[1], **Forsberg L**[1], **Wheeler G.C**[1]

1. Peter MacCallum Cancer Centre, East Melbourne, VICTO, Australia

Aims

The Peter MacCallum Cancer Centre Late Effects service was established in 1999 to provide follow up of long-term cancer survivors of paediatric malignancies, and was the first service in Australia of its type in an adult hospital. The service currently provides ongoing care for 1006 patients, and receives up to 100 new referrals annually. With ever rising numbers of cancer survivors and demands on the service, it became increasingly difficult to provide ongoing care for existing patients whilst accepting increasing numbers of newly referred complex cancer survivors.

Methods

In 2008 a GP Shared Care program was established to provide an alternative model of care to manage increasing clinic demand and facilitate best practice care of patients in the community setting with their own GP. This included:

- The establishment of a GP Liaison position, employing a general practitioner who had a clinical role in the Late Effects service and implemented the program;
- Development of long-term follow up guidelines to provide advice on best practice screening and surveillance of late effects of cancer therapies;
- Risk stratification of patients to surveillance levels depending on complexity of needs and follow up requirements;
- Coordination of follow up with the patient's own GP, and provision of clinical support.

Results

In 2011, 13 patients were allocated to GP follow up; this number has increased annually such that 114 patients were allocated to GP shared care follow up in 2016. The shared care model supports screening and surveillance of late effects of treatment and ongoing management of chronic complications for cancer survivors close to home, with their regular GP, in a convenient and timely manner.

Conclusions

This model provides best practice care of long term survivors of complex cancer treatment which is sustainable and highly acceptable to specialist clinicians, patients and their GPs.

76

Key strategies and learning in the development, sustainability & transferability of a model of survivorship care

Kerry Shanahan[1], Kathryn Wallace[2], Bruce Mann[1], Meron Pitcher[3], Caroline Baker[2], Leanne Storer[3]

1. Royal Melbourne Hospital, Parkville, VIC, Australia

2. Austin Health, Heidelberg, VIC, Australia

3. Western Health, Footscray, VIC, Australia

Aim: Develop a comprehensive end of treatment survivorship program for patients with early breast cancer. Demonstrate, based upon key strategies and learning, this model of care can be transferred, adapted and implemented according to the individual needs of an organisation.

Method: From 2010 three major metropolitan Melbourne based Breast Services developed a comprehensive survivorship program for women with early breast cancer who had completed their active hospital based treatment. Working collaboratively with Primary Health Networks and a community based peer support service this work was funded by the Victorian Department of Health & Human Services (DHHS). A nurse-led consultation, survivorship care plan & follow-up guidelines were developed, implemented & evaluated.

Based upon the establishment of this as a sustainable model of survivorship care, the DHHS extended funding to other Melbourne Metropolitan Breast Services. In addition, one of the lead sites provided mentorship, transfer of knowledge, processes and resources developed.

Results: Across the four sites more than 760 nurse-led consultations have been completed. Evaluation of patients, GPs and specialists involved identified overwhelmingly positive feedback including improved, individualised, consistent & co-ordinated follow-up care. Early transition to shared primary and hospital based follow-up care is achieved which increases capacity for new and complex review patients within the specialist outpatient service.

Conclusion: The survivorship program is being embedded as part of routine practice at the listed sites, and demonstrates that this model of care can be transferred across Breast Services. It is a model that can also be adapted to other tumour streams. Fostering collaborative partnerships between acute services, primary care, consumers and community based services enables a comprehensive approach to developing new models of survivorship care. Streamlining processes and sharing of knowledge and resources is an important part of developing a sustainable and transferable model of care.

77

Breast cancer survivors' long-term goals for participating in an online physical activity program. Lessons learned in the iMove more for life RCT

Camille E Short[1], Erica L James[2], Amanda L Rebar [3], Mitch J Duncan[2], Kerry Courneya[4], Ron C Plotnikoff[2], Rik Crutzen[5], Niranjan Bidargaddi Parameshwar [6], Corneel Vandelanotte [3]

1. The University of Adelaide, Adelaide, SA, Australia

2. University of Newcastle, Newcastle , NSW, Australia

3. CQUniversity , Rockhampton, QLD, Australia

4. University of Alberta, Edmonton, Canada

5. Maastricht university, Maastricht , Netherlands

6. Flinders University , Adelaide , Australia

Background: Patient-centered interventions are needed to support breast cancer survivors to increase their participation in physical activity. Such interventions should accommodate the goals of the user. We conducted an online intervention study with post-treatment breast cancer survivors (n = 492). As part of this intervention, participants were prompted to write down their long-term physical activity goal. Aim: The current study aimed to identify common themes in participant's goal data and highlight possible intervention design implications. Method: Of the 492 participants enrolled in intervention, 370 (75%) specified their long-term (‘1-year from today’) goal. Data were analysed using an inductive thematic analysis approach. Results: The majority of participants (60%) reported multi-faceted goals, consisting of two or more outcomes they would like to achieve (e.g., “Losing 10kg, walk for 30 minutes every day, and being able to walk around Singapore during our holidays”). Overall, the most common goals related to having a regular exercise routine, being satisfied with body weight or image, increasing fitness and strength and improving current health issues. While these goals are in line with previous research examining key exercise motives among breast cancer survivors, we found that there was considerable variability in goal scope between individuals. For example, the extent of weight loss desired ranged from 2kg-30kg. Further, some people reported weight loss goals using other metrics, such as clothes sizes, and waist circumference. Discussion: Our study provides a nuanced understanding of breast cancer survivors’ long-term goals for participating in an intervention program. This information is invaluable for designing future interventions that better accommodate individual's needs.

78

Models of follow-up care in Australia and New Zealand: challenges to implementing optimal survivorship care in paediatric cancer

Christina Signorelli[1], Claire E Wakefield[1], Jordana K McLoone[1], Joanna E Fardell[1], Renae Lawrence[1], Michael Osborn[2], Jo Truscott[3], Heather Tapp[4], Richard J Cohn[1]

1. Sydney Children's Hospital; UNSW Australia, Randwick, NSW, Australia

2. Royal Adelaide Hospital; Women's and Children's Hospital, Adelaide

3. Christchurch, New Zealand, Christchurch

4. Women's and Children's Hospital, Adelaide

Aims: Long term follow-up (LTFU) care is recommended for childhood cancer survivors, who remain at risk of developing life-altering and/or threatening diseases following curative treatment. This study reports on current childhood cancer survivorship care practices across Australia and New Zealand (ANZ), highlighting the challenges long term follow-up clinics face.

Methods: We conducted semi-structured, telephone interviews with the pediatric medical director and clinical nurse consultant from all 11 LTFU clinics at tertiary referral paediatric oncology units across ANZ (n=19; 100% response rate). Data was analyzed thematically using NVivo10.

Results: No uniform model of care for childhood cancer survivors exists in ANZ. Each pediatric oncology centre organically developed its own model of survivorship care, shaped by local resources, staff interest/expertise, institutional policy, and variably employing international guidelines. This has led to a resource duplication between clinics, for example in the development of survivorship care plan templates or general clinic systems. Participants identified three central challenges to the provision of best-practice LTFU care, including insufficient funding, unclear transition pathways and need for further research and collaborative efforts. Lack of funding, especially recurrent funding, was a challenge reported in most clinics, which relied on volunteered time. All participants unanimously identified limited options for transitioning older survivors out of pediatrics to adult care, with highly varying practices in preparation, transition age, resources, and pathways across clinics. Though participants recognised a prescriptive model of care as potentially unfeasible, they endorsed a national, or bi-national, model of care that could be tailored to meet their local needs.

Conclusions: The lack of an accepted model of childhood cancer survivorship care across ANZ prevents the optimal delivery of care to this population. Improved solutions are urgently needed for transitioning survivors to appropriate care entering adulthood, in addition to more securing funding to facilitate the growing number of survivors.

79

Fit to Thrive: Outcomes of a specialised exercise program to support patients with a haematological malignancy

Michele Leis[1], Maryanne Skarparis[1]

1. Leukaemia Foundation, Dutton Park, QLD, Australia

Research is increasingly showing that physical activity for cancer patients before, during, and post-treatment can improve muscular endurance, decrease symptoms of fatigue, improve balance and flexibility, increase muscle mass, and improve quality of life. A collaborative approach between the Leukaemia Foundation of Queensland and Aspire Fitness and Rehabilitation led to the development of an individualised exercise program, aimed at supporting the growing evidence of the benefits of physical activity for people living with a blood cancer.

Fit to Thrive is a 12 week specialised exercise program which aims to assist patients both individually and in a group setting. This allows them to meet their individual goals, enhances their quality of life, and provides them with the best practice in patient care.

Over a two year period, the program has recruited 147 participants (female = 70, male = 77), who ranged in age from 17 to 80 years old and had been diagnosed with a haematological malignancy. Participants completed objective measures and an online questionnaire at week one, seven and twelve. Participants were assessed against their own individual responses and improvements on a number of clinically relevant subjective and objective measures.

Based on the accumulated data and anecdotal feedback, the program has been able to deliver an individualised approach to rehabilitation with statistically significant changes in functional strength and endurance, fatigue and psycho-social measures. Results at the six and twelve month time point also indicated that the improvements had a long-term impact, with all key measures remaining higher than prior to commencement of the program. The outcomes of this pilot study into exercise based interventions for patients may begin to act as a scientifically relevant way to demonstrate the positive outcomes for fatigue tolerance, self-efficacy and psycho-social measures in patients with a haematological malignancy.

80

A systematic review of late effects in survivors of stage I seminoma

Jennifer Soon[1], Javier Torres[1], Angelyn Anton[1], Ruth Lawrence[2], Phillip Parente[1, 3], Joseph McKendrick[1, 3], Ian Davis[1, 3], Carmel Pezaro[1, 3]

1. Cancer Services, Eastern Health, Box Hill Hospital, Victoria, Australia

2. Library Services, Eastern Health, Box Hill Hospital, Victoria, Australia

3. Eastern Health Clinical School, Monash University, Box Hill, Victoria, Australia

PURPOSE: Testicular seminoma mainly affects young men in the second to fourth decades of life. Stage I seminoma has a cure rate approaching 99%, resulting in long-term survival after treatment. Toxicities or complications of treatment for more extensive seminomas are known to cause long-term morbidities, however little has been documented regarding patients with stage I seminoma following curative treatment. In this systematic review, we examined existing literature regarding late effects in patients with stage I testicular seminoma treated with surgical orchiectomy.

METHOD: Publications were identified through an electronic literature search using the MEDLINE, EMBASE and PsychInfo databases, identifying late effects in cohorts with stage I seminoma. Effects were classified as physical (bone health, cardiac, metabolic syndrome, renal function, second malignancy, fertility, hypogonadism and sexual function) or psychological (cognition, depression, fatigue and quality of life).

RESULTS: 600 articles were screened to identify 128 relevant studies. Overall there was conflicting evidence about increased cardiovascular risk in patients treated with orchiectomy. As expected, orchiectomy alone was not associated with osteoporosis or renal impairment. Increased rates of second malignancy was restricted to patients receiving multi-modality treatment. 5 studies showed an increased incidence of contralateral testicular cancer. Baseline sperm counts were low in most patients however data regarding fertility was inconsistent. Psychological late effects included anxiety and chronic fatigue, with diverging data regarding depression, quality of life, suicidal risk and sexuality. Heterogeneity of study design and under-reporting of effects contributed to uncertainty regarding the true incidence and clinical significance of late effects.

CONCLUSIONS: Additional data are needed on the prevalence of late effects following orchiectomy alone. The curability of stage I seminoma and the range of possible late effects of treatment support the need for long-term monitoring alongside standard cancer surveillance. Awareness and screening for these late effects may prevent further morbidity in these men.

81

Low referral of breast cancer survivors to rehabilitation and wellness services: A project to improve service provider networking

Denise Stewart[1]

1. Breast and Shoulder Rehab, Alderley, QLD, Australia

Pain, poor upper body performance measures and lower QOL are commonly reported by long term survivors of breast cancer. Low referral rates by cancer care doctors has been identified as a barrier since 2012. This barrier of very low referral rates for breast cancer survivors to specialist rehabilitation and wellness services continues to be reported by specialist practitioners across the world and from

Australian data published in 2015. The online Summit format has been used over the last 3 years, in other areas of health, as a means of increasing awareness of specific health issues and solutions. The online health summit format using a variety of health care experts as speakers was the basis for this project. The creation of a virtual team of local and international specialists provides an opportunity to establish a new dialogue between presenters.The availability of free access was also employed to reduce financial and travel barriers with the aim of having more health professionals attending the event. The data collected from the Summit will be presented: connections between the presenters, number of health professional viewers and number of virtual peer to peer networking opportunities created. Awareness of impairments, survivor needs, solutions and referral confidence by Summit listeners will be presented.

82

Testing the effectiveness of online training delivery targeted at improving healthy living knowledge, skills and confidence of breast cancer survivors

Fiona Tansley[1], **Janelle Woods**[1], **Bethany Newman**[1], **Amanda Winiata**[1], **Kim Hyman**[1], **Sarah Lausberg**[1], **Jenny Anderson**[1]

1. Breast Cancer Network Australia, Camberwell, VIC, Australia

Background: For women diagnosed with breast cancer, regular exercise and healthy eating during and following treatment has been shown to improve both physical and emotional health, overall quality of life and may also reduce the risk of breast cancer recurrence.

Aim: To develop an online training program that is accessible and equitable to all breast cancer survivors that increases healthy living knowledge, skills and confidence.

Method: The online program was developed in collaboration with exercise physiologists, dietitians and key cancer stakeholders. It has three modules (health and wellbeing, behaviour change, emotional wellbeing) comprising interactive text, image, video and workbook activities. The program ran for eight weeks. At the end of each module participants completed a quiz and were required to obtain an 80% correct response rate to pass. A post-program online evaluation survey was emailed to participants on program close. Evaluation will comprise data analysis of post-program evaluation survey results, module completion rates along with module quiz proficiency scores.

Results: In total, 112 participants (44% from a rural location) registered. The program ran August to October 2016 and evaluation will be completed in November. Results will be presented on improvements in participant knowledge, skills and confidence in the areas of physical activity, healthy eating, behaviour change and emotional wellbeing. Anecdotal evidence collected so far indicates the program offered improved access and equity to information and resources especially to individuals who face barriers such as living in rural locations.

Conclusions: Findings from this project will inform other health promotion and cancer organisations about whether an online platform is an effective and accessible delivery method for improving healthy living knowledge, skills and confidence of breast cancer survivors. Further work will need to be done to measure long term behaviour change and improved cancer survivorship outcomes.

83

Development of a Survivorship Care Plan and Treatment Summary for Lymphoma Survivors

Karen M Taylor[2, 1], **David Joske**[3, 4], **David Oldham**[3], **Leanne Monterosso**[1, 5, 6]

1. School of Nursing and Midwifery, University of Notre Dame Australia, Fremantle, Western Australia, Australia

2. Western Australia Cancer and Palliative Care Network, East Perth, WA, Australia

3. Sir Charles Gairdner Hospital, Nedlands, WA, Australia

4. University of Western Australia, Crawley, WA, Australia

5. Centre for Nursing & Midwifery Research, St John of God Hospital, Murdoch, Western Australia, Australia

6. School of Nursing and Midwifery, Edith Cowan University, Joondalup, Western Australia, Australia

Aims: To feedback on the innovative development of a lymphoma SCPTS that provides written information to survivors and health care providers with clear delineation of future care responsibility. Lymphoma is a commonly diagnosed cancer that requires complex and aggressive treatment regimens. Given the absence of follow-up guidelines and an increased risk of bio-psycho-social impacts from disease and treatment, there is potential for poorer overall health outcomes. Survivorship care plans and treatment summaries (SCPTS) are recommended to facilitate individualised and holistic survivorship follow-up to patients and health care providers. They communicate: diagnosis and treatment-specific information; potential late effects; and health promotion.

Methods: A comprehensive integrative review of literature and current SCPTS was undertaken. No suitable lymphoma-specific SCPTS were found. A lymphoma SCPTS was therefore developed to provide: a concise diagnosis/treatment summary; tailored late effects information; general healthy lifestyle behaviour and screening information. The SCPTS also encourages survivors to generate their key health issues, health goals and the actions they will take to achieve goals.

Results: Lymphoma survivors (n=6) and clinicians (including GPs) (n=6) perspectives were sought to determine relevance of proposed SCPTS items. Items were assessed for content clarity, apparent internal consistency and content validity. Content validity index (CVI) scores were generated for each item. Overall, mean CVI results for included items were: clarity 0.985; apparent internal consistency 0.975; content validity 0.895. Low scoring items were removed. Feedback indicated GPs valued a short and concise treatment summary.

Conclusions: Nurses have established expertise in health promotion, information, support and resource provision, and therefore can develop and disseminate innovative SCPTS to facilitate communication between the survivor, specialist and primary care. Providing tailored SCPTS may empower survivors to assume responsibility for future surveillance and disease management, thereby facilitating engagement in a future healthy lifestyle.

84

Facilitators and barriers to participation in a weight management study for cancer survivors: A qualitative exploration

Jane D Turner[1, 2], **Sim Yee (Cindy) Tan**[2, 3], **Haryana M Dhillon**[1], **Natalie Stefanic**[1], **Janette L Vardy**[4, 2]

1. Centre for Medical Psychology and Evidence-based Decision-making, The University of Sydney, Sydney

2. Concord Cancer Centre, Concord, NSW, Australia

3. Nutrition and Dietetics Department, Concord Hospital, Concord, NSW, Australia

4. Sydney Medical School, The University of Sydney, Sydney

Aims

For cancer survivors, obesity and lack of physical activity contribute to disease burden and poorer disease and health-related outcomes. Despite recommendations to remain physically active, have a diet high in fruit and vegetables, and maintain a healthy weight, the majority of cancer survivors do not meet these criteria and access to healthy lifestyle programs are not routinely integrated into survivorship care. This study aimed to qualitatively explore the barriers and facilitators to participating in a 6-month (twice weekly exercise and once weekly nutrition) weight management program (WMP) for overweight/obese cancer survivors at the Sydney Survivorship Centre (SSC).

Methods

Overweight/obese (BMI ≥25kg/m^2) adults with localised cancer who completed the six month WMP participated in recorded, semi-structured telephone interviews. The interviews were transcribed verbatim and themes derived from the data were coded using a framework analysis approach.

Results

Ten women with median age 56 years (range 45-71) participated in the telephone interview. Tumour groups represented: breast (n=6), colorectal (n=3), and Non-Hodgkin's lymphoma (n=1). Participants identified several things that facilitated adherence to the intervention: support from program staff and other participants; tailoring of the program to their needs and limitations. Interactions between study participants were valued; individuals felt "more comfortable" being around "like-minded people". Participants reported not feeling pressure to perform and being able to share their feelings and experiences with others survivors more easily than their friends or family. Some participants benefitted from individually prescribed programs tailored to their needs and felt empowered to take control of their health. Barriers to adherence include: limited session times; return to work; and, commute time.

Conclusions

Our study confirms that overweight/obese cancer survivors are willing to commit to, and attend, an intensive hospital-based exercise and nutrition WMP, where they felt supported, heard, encouraged, and not judged.

85

Physical and psychological health status of cancer survivors following primary adjuvant treatment

Janette L Vardy[1, 2, 3], **Cindy Tan**[4], **Jane D Turner**[2], **Kim Kerin-Ayres** [4], **Cole Deguchi**[4], **Sonia Khatri**[4], **Sue Butler**[4], **Lynda Wignall**[3], **Ilona Cunningham**[4], **Ashanya Malalasekera**[1], **Haryana M Dhillon**[2]

1. University of Sydney, Concord, NSW, Australia

2. CeMPED, University of Sydney, Sydney, NSW, Australia

3. Concord Cancer Centre, Sydney, NSW, Australia

4. Concord Cancer Centre, Concord, NSW, Australia

Aims:

Cancer survivors experience ongoing health problems compared to the general population. The Sydney Survivorship Clinic aims to help cancer survivors better manage their disease and treatment effects. Here we report the health status of cancer survivors post primary adjuvant treatment.

Method:

Cancer survivors completed questionnaires assessing: distress, symptoms, quality of life (QOL), diet and exercise before attending the Sydney Survivorship Clinic. Attendees were seen by a multidisciplinary team (medical oncologist/haematologist, cancer nurse specialist, dietitian, clinical psychologist and exercise physiologist).

Results:

A total of 242 survivors attended an initial clinic visit from September 2013 to October 2016 with 225 survivors included in analysis: median age 55years (range 21-86). Median time from diagnosis: 11.3 months (range 1.6 - 1284). Tumour types: breast 48%, colorectal 32%, haematology 16%, other 4%. Most (92%) had undergone surgery, 89% had received chemotherapy, 44% radiotherapy. Most common symptoms of at least moderate severity were: fatigue (55%), insomnia (46%), pain (44%), anxiety (40%), numbness (39%), sore hands/feet (38%), trouble concentrating (35%), hot flushes (34%), memory problems (33%). Half (51%) had distress thermometer score of 4+, meeting screening guidelines for further investigation. Overall, 63% were rated by the psychologist as having 'fear of cancer recurrence'; 28% were referred for follow-up, 6% already linked with psychological services.

The mean overall QOL score (FACT-G) was 80 (SD 17), which is comparable to other cancer survivor cohorts, with physical and social well being the domains most impacted.

Average BMI was 28.1kg/m^2 (range 16.5 – 59.1kg/m^2); 57% were overweight or obese, particularly high in breast (63%) and colorectal cancer (66%) survivors. Only 40% of survivors reported meeting physical activity guidelines.

Conclusion:

Distress, fatigue, obesity and sedentary lifestyle are common, persisting years after cancer diagnosis. The Survivorship clinic identifies important issues for cancer survivors after adjuvant treatment and facilitates effective management of these concerns.

86

We need to be measuring inflammatory biomarkers: A preclinical model of breast cancer-induced cognitive impairment points to neuroinflammation as the mechanism

Adam K Walker[1], Erica K Sloan[1]

1. Monash Institute of Pharmaceutical Sciences, Parkville, VIC, Australia

Aims: Cognitive impairment in cancer patients often presents before treatment, called “cancer brain”. Anxiety of diagnosis is usually identified as the source of cancer brain but the tumour itself may also play a role. We aimed to use a breast cancer mouse model to identify the mechanisms and biomarkers of cancer brain in the absence of anxiety related to diagnosis, which is unavoidable in patient studies.

Methods: Mice were injected with a syngenic breast cancer cell line or vehicle into the orthotopic site. Bioluminescence imaging was used to monitor cancer progression. Memory impairment was assessed using validated behavioural tests for memory in mice. To determine whether secreted factors from tumour cells were sufficient to induce memory impairment, a second group of mice were treated with daily injections of tumour-conditioned media and assessed for memory impairment. Inflammatory profiles of tumour bearing vs control mice were assessed in the brain, spleen and plasma.

Results: Mice exhibited memory impairment as early as 3 days after tumour cell injection ($p < 0.05$). Injection of secreted factors was sufficient to induce memory impairment in the absence of tumour cells ($p < 0.05$). Increased splenic and plasma proinflammatory cytokines and reduced anti-inflammatory IL-10 was also observed in the brains of tumour-bearing mice compared to controls and in the tumour-conditioned media ($p < 0.05$).

Conclusions: These mouse models of breast cancer show that a peripheral tumour can drive cognitive impairment via neuroinflammation in addition to the psychosocial factors usually associated with cancer brain. Peripheral markers of inflammation directly matched those in the memory centres of the brain suggestive that measurement of the inflammatory profile of cancer patients in blood may serve as a valuable prognostic indicator of cognitive impairment and susceptibility. NSAIDs may serve as an early preventative measure against cancer brain.

This work was supported by the National Breast Cancer Foundation (PF-15-014).

87

Development of written resources with and for culturally and linguistically diverse cancer survivors in Australia: lessons learnt

Georgina E Wiley[1, 2], Amanda Piper[2], Phyllis Butow[3], Penelope Schofield[4, 5], Melanie Price[3], Jane Roy[6], Fiona Douglas[7], Linda Nolte[8], Michael Jefford[2]

1. Peter MacCallum Cancer Centre, Melbourne, VICTORIA, Australia

2. Australian Cancer Survivorship Centre - A Richard Pratt Legacy, Peter MacCallum Cancer Centre , Melbourne, Victoria, 3000

3. Psycho-oncology Co-operative Research Group (PoCoG), University of Sydney, Sydney, NSW, Australia

4. Department of Cancer Experience Research, Peter MacCallum Cancer Centre, Melbourne, Victoria, Australia

5. Swinburne University, Melbourne, Victoria, Australia

6. Cancer Council Australia, Sydney, NSW, Australia

7. Cancer Council Victoria, Melbourne, Victoria, Australia

8. Austin Health, Melbourne, Victoria, Australia

Background

Australia is a multicultural nation with a large migrant population. Migrants with cancer report inferior quality of life and need for more information in their language. We developed new written resources for people who speak Cantonese, Mandarin, Greek, Italian, Vietnamese and Arabic.

Aim

To describe lessons learnt from developing culturally appropriate written information resources with and for Arabic, Italian, and Vietnamese cancer survivors and carers.

Methods

Information needs of survivors from these language groups and guidelines for the development of resources for culturally diverse populations were identified through literature. Community consultation was undertaken with focus groups (FG) in each language with survivors and carers. Content was developed and tested with health professionals who spoke the appropriate language and FG participants ensuring relevance and appropriateness; resource design and dissemination were informed by ongoing community consultation.

This process recognised a number of development stages as vital. Many stages were identified as unique to developing resources for culturally diverse populations.

Results

New print resources were developed and reviewed by survivors and carers. Reviewers felt that there was a correct amount of information and that content was relevant and reassuring. No reviewers rated the resources negatively. Comments validated feedback received in the FGs. The development of bi-lingual resources provided additional ways for the resources to be used and disseminated.

Five key principles were identified as being vital to the development of culturally appropriate resources with and for cancer survivors and their carers: (1) community engagement and consultation (2) content development (3) translation and review process (4) design (5) sustainability and dissemination.

A systematic process was developed to guide the development of future resources.

Conclusions

Cultural sensitivity should be at the core of information resource development for culturally diverse groups. Stakeholders and lay persons from the intended ethnic-minority communities should be involved in the development and formative evaluation of resources to ensure cultural relevance.

Author Index

Sponsors & Exhibitors

Abbvie
Bronze Sponsor, Table #4
www.abbvie.com.au
AbbVie is a global, research-based biopharmaceutical company formed in 2013 following separation from Abbott Laboratories. The Company's mission is to use its expertise, dedicated people and unique approach to innovation to develop and market advanced therapies that address some of the world's most complex and serious diseases. Together with its wholly-owned subsidiary, Pharmacyclics, AbbVie employs more than 28,000 people worldwide and markets medicines in more than 170 countries. Over 31,000 people in Australia currently benefit from biologics and specialty-focused AbbVie products. AbbVie is driven by responding to areas of unmet clinical need, including some of the most challenging and aggressive cancers. AbbVie globally has 190 active oncology clinical trials with 13 molecular compounds ranging from phase I, II and III representing 19 different cancer or tumour types.

Seqirus
Supporting Sponsor
www.seqirus.com.au
At CSL, we're proud of our heritage, and as we celebrate our centenary, we remember that it all started here in Australia. Set up by the government during WWI to protect the health of a nation, we have since grown to become a global leader in biotherapeutics. We are privileged to work with the smartest minds and we thank the many doctors, nurses and scientists who have contributed to our achievements. Seqirus, a CSL company, is a leading provider of essential vaccines, pharmaceuticals products such as Palexia® and Versatis®and diagnostic reagents. As the second largest influenza business in the world, Seqirus operates Australia's only onshore manufacturing facility for seasonal and pandemic influenza vaccine, and produces medicines of national significance including antivenoms and the Q fever vaccine. We are CSL, and we're just getting started.

Australian Lymphology Association
Table #6
www.lymphoedema.org.au
The Leukaemia Foundation is the only national charity dedicated to helping Australians with leukaemia, lymphoma, myeloma and related disorders survive their blood cancer and live a better quality of life. The Foundation invests in research and supports patients by providing support services like accommodation, transport, education, emotional and financial support.

Breast Cancer Network Australia
Table #5
www.bcna.org.au
Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer, and consists of a network of more than 100,000 individual members and over 300 Member Groups. BCNA supports, informs, represents and connects people affected by breast cancer. BCNA works to ensure that they receive the very best support, information, treatment and care appropriate to their individual needs.

Cancer Care Centre – Table #7
Cancer Care Centre, which has been operating since 1985, offers a range of complementary health services specifically designed for cancer patients. These include oncology and lymphatic massage, counselling, meditation, gentle yoga, support groups, a library facility and a variety of workshops and classes. The staff also offers "Pathways" appointments for potential clients who may be anyone affected by cancer. The appointment, of one hour's duration, is free of charge and discussion centres on the client and their needs and expectations. From this introduction, the support worker is able to discern the best services to offer. The Centre is almost entirely staffed by volunteers. The therapists and counsellors are fully qualified, and the support workers undergo regular training by both professional specialists and by senior support workers. "Journey to Wellness" is the Centre's 'flagship 6 week course which runs several times during the year, during which attendees learn of, and discuss, all aspects of the cancer journey in a supportive, safe and friendly environment. This course is facilitated by trained, skilled staff well experienced in working with cancer patients. The Centre also offers numerous other courses such as Exercise your Lymphatics, Vegetarian cooking classes & Seeds for Health Organic Gardening Course.

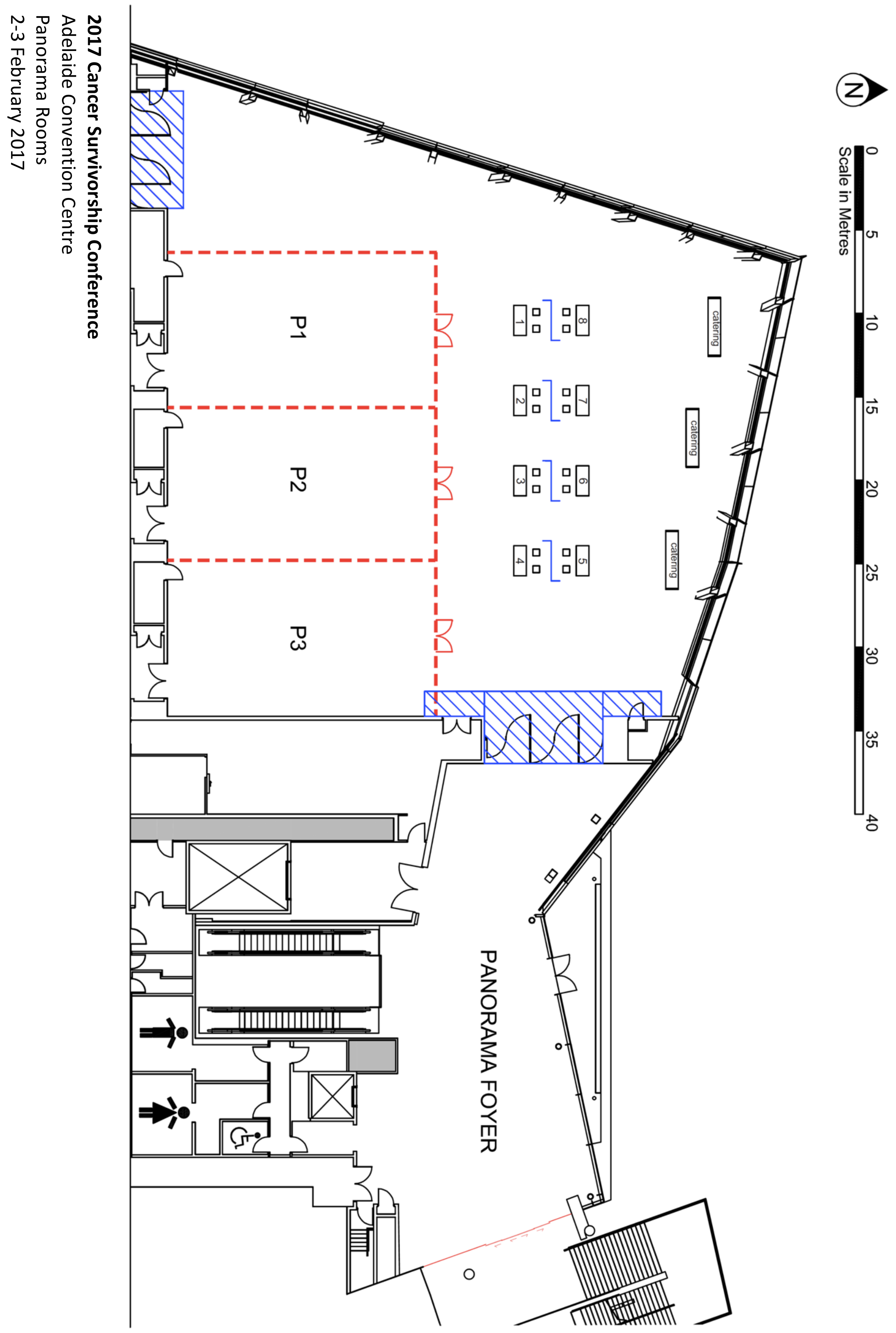
CanTeen *www.seqirus.com.au*
Table #2
www.canteen.org.au
We get it. Just when life should be full of possibilities, cancer crashes into a young person's world and shatters everything. CanTeen is the game changer. We help young people cope with cancer in their family, rebuild their foundations and connect with others in the same boat.

Ipsen
Table #8
www.ipsen.com.au
Ipsen provides specialty medicines and quality services to Healthcare Professional and their patients suffering from debilitating diseases. At Ipsen, our passion is improving the lives of patients. We do this by working together to build partnerships based on trust and mutual respect with Healthcare Professionals. We deliver tailored solutions through our agility and innovation and we strive to be even better tomorrow than we are today.

Leukaemia Foundation
Table #1
www.leukaemia.org.au
The Leukaemia Foundation is Australia's peak body for blood cancer, funding research and providing free services to support people with leukaemia, lymphoma, myeloma, MDS, MPN and related blood disorders, and their families. Our services, delivered by a national team of around 50 support service staff who are qualified in nursing and allied health, include emotional support, information, education, accommodation, transport, practical assistance and advocacy.

Peter MacCallum Cancer Centre - Australian Cancer Survivorship Centre (ACSC)
Table #3
www.petermac.org/cancersurvivorship
The Australian Cancer Survivorship Centre (ACSC) was established with funding from The Pratt Foundation, Department of Health Victoria and Peter MacCallum Cancer Centre. Our vision is to optimise the health and wellbeing of cancer survivors and their carers. We focus primarily on the post-treatment phase to maximise our impact**.**

Exhibition Floor Plan



Notes

Notes

Notes

Notes