

## Poster discussion

Flinders Centre for Innovation in Cancer  
2015 Survivorship Conference

Plenary 5 – Models of care  
Saturday February 7 2015

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## Posters in context

- Challenges in providing ideal post-treatment care
  - Large numbers of survivors
  - Broad range of issues survivors may experience
  - Limited health workforce
  - Few proven models of care
  - Gaps in evidence (consequences, prevention and management, models of care)

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## Posters in context

- Some questions
  - What issues do survivors experience?
  - Do we have a system to track patient / survivor experience?
  - How do survivors direct the development of new models of care?
  - What are the appropriate research priorities in cancer survivorship?

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## Posters in context

- Some questions
  - How to tailor care to risk and need?
  - Who is best placed to provide post-treatment care?
  - How can survivors be supported to self-manage?
  - How to link survivors to evidence-based healthy lifestyle interventions?
  - What is the role of community providers? NGOs?

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## Posters in context

- Some questions
  - Evaluating and implementing novel models of care
  - Evaluating 'follow up' strategies
    - Are they evidence-based?
    - Are they cost effective?
  - How to overcome barriers to reform of the system?
  - What is the role of consumer advocacy?

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## Posters in context

- Priority-driven survivorship care / co-design with survivors
  - Why aren't we 'Measuring what matters to cancer survivors' in Australia? (Ms Julie Marker)
  - Research on cancer survivorship in Australia: current status, gaps and needs (Dr Agnes Vitry)
  - Strengthening survivors' roles in clinical trials advisory groups (JCAG, PC4, PoCoG)



## Posters in context

- Understanding survivor experience / needs
  - Survivorship challenges for Australian women with breast cancer (Ms Michelle Marven)
- Models of care / workforce
  - Defining the role of occupational therapy in cancer survivorship (A/Prof Lynette Mackenzie)



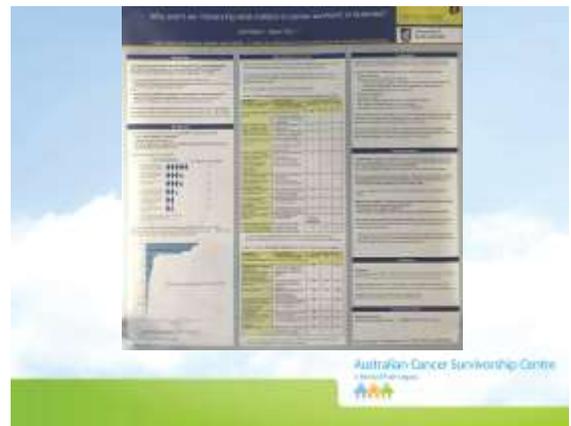
## Posters in context

- Models of care / supported self management
  - Hospital-based supported self-management intervention for colorectal cancer survivors: acceptability and feasibility in New Zealand (Ms Inga O'Brien)
  - Coping-Together: A self management intervention to address the psychosocial needs of couples affected by cancer (Dr Janelle Levesque)



## Posters in context

- Interventions to promote health and wellbeing
  - Fit to Thrive: A specialised exercise program to support patients with a haematological malignancy (Ms Maryanne Skarparis)



**ROUTES FROM DIAGNOSIS**

**Quality of Life of Cancer Survivors in England**

**open** Patient-reported outcomes of cancer survivors in England 1-5 years after diagnosis: a cross-sectional survey

Adrian W. Haines<sup>1</sup>, Laura E. Franks<sup>2</sup>, Jessica Crooks<sup>3</sup>, Huihui Heilbrunn<sup>4</sup>, Eric J. A. Morris<sup>5</sup>, Greg Hayward<sup>6</sup>, Mike Dickson<sup>7</sup>

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NEWS

...to what the national education system is doing

NEWS

...to what the national education system is doing

## Comments

- Priorities and concerns of survivors
- Data collection and monitoring
  - Patient-reported outcome measures
    - Health and wellbeing
    - Quality of life, unmet needs
  - Patterns / quality of care, equity
  - Long term impacts
  - Recurrence

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## Comments

- Outcomes for monitoring
- Population-based data collection
- Predictive models
- Funding
- Advocacy

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Slide # 30

**Research on cancer survivorship in Australia: current status, gaps and needs**

Agnes Vitez<sup>1</sup>, John Mather<sup>1</sup>

1. University of South Australia, Adelaide, SA, Australia
2. Cancer Inkubator SA, Adelaide, Australia

This presentation will review the current status, gaps and needs for research on cancer survivorship in Australia using both a researcher's and survivor's perspective.

Cancer survivors are heterogeneous with regards to their survivorship care needs. Research addressing cancer survivors' long-term medical, psychosocial, and practical needs across the survivorship trajectory is needed.

In 2009-2012, only 7% of funded research focused on cancer control, survivorship and outcomes research. While there are already national epidemiological statistics on cancer prevalence and incidence, there is still inadequate knowledge on long-term cancer survivorship which is mainly based on cohorts, one-off surveys. Research on late adverse effects of treatment of adult cancer survivors is sparse. Research on current cancer care practices and associated health outcomes is restricted by existing barriers to linkage of routinely collected data such as genotyping data. There is also limited research on the development and evaluation of interventions to improve health and quality of life of adult cancer survivors.

Research on cancer survivorship is essential to inform the development of a national strategy for achieving high quality cancer survivorship care. The international literature endorsed cancer survivorship is useful but we have limited detailed data from within our own health system. Progress is being made through the development of data linkage facilities and best practice guide to data access. Cancer survivors do support efforts to ensure that publicly funded datasets can be used effectively and securely to address gaps of current research. Cancer survivors also recommend that more research should be done to better understand the needs of cancer survivors and how to best address the long-term challenges in their health care.

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**Research on cancer survivorship in Australia: Current status, gaps and needs**

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## Research questions

- Effects of treatments
  - Understanding mechanisms
- Needs and characteristics of unique populations
- Testing models of care
- Effective interventions
- Tools for measurement in research



## Comments

- Amount of funding for 'survivorship' research is low
- Australia has significant capability
- Better national coordination?
- NGOs as funding sources
- Is there a place for advocacy?

Abm # 55

### Strengthening survivors' roles in cancer trials advisory groups

Juliet Cunningham-Adams, Brian LICAM<sup>1,2</sup>

1. Primary Care Collaborative Cancer Clinical Trials Group (PCC), Perth, WA
2. Psycho-Oncology Clinical Trials Group (PCCOG), Sydney, NSW

#### Introduction:

Cancer survivors and carers play a vital role in the 14 national cancer clinical trials groups. This includes our input around the research study design, outcome measures, the potential of burden, inequality and challenges for trial participants, suggestions for improving recruitment, refining study and information materials and general 'consumer perspective' of the importance or priority of study objectives.

The Local Community Advisory Group (LCAG) for the Psycho-Oncology (PCCOG) and Primary Care Collaborative Cancer Clinical Trials (PCC) Groups has implemented a peer support program for sharing ideas and to strengthen the collaboration, capability and confidence of members to operate in this unfamiliar role.

#### Method:

The LCAG was first established in mid 2009 with 10 members, and the peer support program was initiated by the PCCOG and PCC Executive Officers. As LCAG members are scattered across Australia, regular contact between peer support pairs is generally by email, skype or phone.

#### Results:

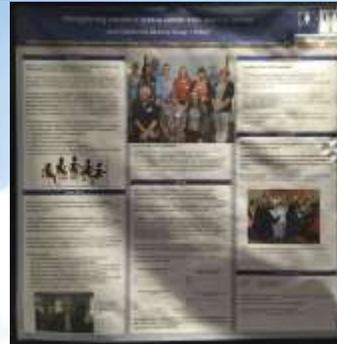
Members of LCAG value and strongly support the formal peer support program.

Unique to LCAG is our broad non-tumour type-specific needs. Trials that are complex interventions and not testing person A/B, and the primary care perspective including cancer prevention, early detection and screening. Hence LCAG members feel we benefit from sharing the diversity of experiences as cancer survivors, carers and/or community members interested in clinical trials to improve cancer care and quality of life outcomes.

We find the quality of feedback, in our advisory roles, is enhanced by this collaborative approach. Feedback from researchers facilitates this greatly appreciate the LCAG input, and increasingly involve us at the early 'concept development' stage of studies.

#### Conclusions:

Participation in clinical trial advisory groups is a steep learning curve for most new-comers. Supporting cancer survivors to share their experience and contribute most effectively to this research measurement is a means to improving the quality and focus of cancer clinical trials.



## Comments

- Peer support for patients, survivors, carers on clinical trial advisory groups
- (not *for* but *with* / nothing about us without us)
- The importance of *enabling*
- A 'seat at the table'
- Survivor-informed / -led research

Abm # 41

### Survivorship challenges for Australian women with breast cancer

Christelle Sanyal, Michelle Marsden<sup>1</sup>, Maxine Moran<sup>2</sup>

1. Breast Cancer Network Australia, Concord, NSW, Australia
2. Breast Cancer Network Australia, Concord, NSW, Australia

The purpose of this research was to identify the needs and challenges, including survivorship issues, facing Australian women with breast cancer.

A mixed methods survey was sent to 9,137 women with a breast cancer diagnosis, with a 14% response rate. Cross tabulation analysis was performed by age, geographical location, diagnosis and time since diagnosis.

39% (3,522) of respondents had been diagnosed between two to five years ago, 26% (2,448) six or more years ago.

86% of respondents had been diagnosed with early breast cancer, 14% were living with secondary breast cancer. 54% were from a major city, 41% from regional, rural or remote areas. 87% of respondents were 50-74 years.

Women were asked to rate a range of challenges that had affected them since their diagnosis. The top five challenges were ongoing wellbeing 53% (n=700), emotional health 50% (n=346), managing side effects 52% (n=680), impact on family and friends 47% (n=583), financial pressures 41% (n=543).

50% of women diagnosed more than two years ago were concerned about their ongoing wellbeing. Younger women (under 55 years) were more concerned about their wellbeing (49%) and emotional health (48%) compared to those over 55 years (57% and 51%).

Qualitative responses (n=202) highlighted information needs for women, with a strong focus on survivorship issues such as physical activity and healthy eating, sexual wellbeing and information for employers when returning to work. Managing hormone treatment side effects was also consistently raised by women.

Next was sought from respondents on specific issues they would like RCNA to advocate on their behalf (n=642). The most significant advocacy issue was the financial cost to women of treatment, 37% (n=248).

Survivorship issues remain key challenges for Australian women, in particular the ongoing psychosocial needs of Australian women and the financial impact of breast cancer.



## Findings

- Top 5 challenges
  1. Ongoing concerns about wellbeing
  2. Emotional health concerns
  3. Managing treatment side effects
  4. Impact on family and friends
  5. Financial pressure

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## Findings

- Unmet need for information
  - Physical activity and health eating
  - Sexual wellbeing
  - For employers and return to work
- Unmet need for assistance with symptom management
- Advocacy around financial costs

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## Comments

- A powerful network of women
- How to meet information needs
  - Provide information early
  - Screen for needs
  - Provide a range of options / supports
    - Link to other resources, NGOs
    - Macmillan / McCabe work
- Advocacy (coalition)

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### Defining the role of occupational therapy in cancer survivorship

**Nicole Buckland<sup>1</sup>, Lynette Mackenzie<sup>1</sup>**  
1. University of Sydney, Lidcombe, NSW, Australia

**Background / Aims:** Increasing rates of cancer survival in Australia indicate that more people are living with long-term side effects of the disease and its treatment, and survivorship is now often considered a distinct phase of cancer care. Whilst occupational therapists play an integral role in multidisciplinary care for many chronic illnesses, and have a recognised role in palliative care oncology, there is little evidence documenting the profession's role in cancer survivorship. This study aimed to explore the views of Australian occupational therapists regarding current and best practice for people with cancer, from diagnosis through to survivorship.

**Methods:** A cross-sectional online survey was developed and distributed through the national Occupational Therapy Australia database to collect responses from occupational therapists in diverse areas of practice across Australia.

**Results:** A total of 224 completed surveys were returned. More than 85% of respondents worked with people with cancer at least occasionally and 10% of practice occurred in community settings. Participants perceived equipment provision to be the most common intervention (94%), followed by energy conservation (90%) and pressure care (89%). Lack of funding for occupational therapy positions and a lack of recognition of the role of occupational therapy by health professionals and consumers were seen as key barriers to best practice.

**Conclusions:** This study highlights the need for occupational therapists to continue to research efforts and to work collaboratively with the multidisciplinary team to develop long-term routine treatment pathways that address the needs of cancer survivors. Recognition of the value of occupational therapy involvement in providing interventions to assist cancer survivors in the community is essential to extend services that are currently available, and education programs are needed to enable occupational therapists to develop their services.

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## Findings

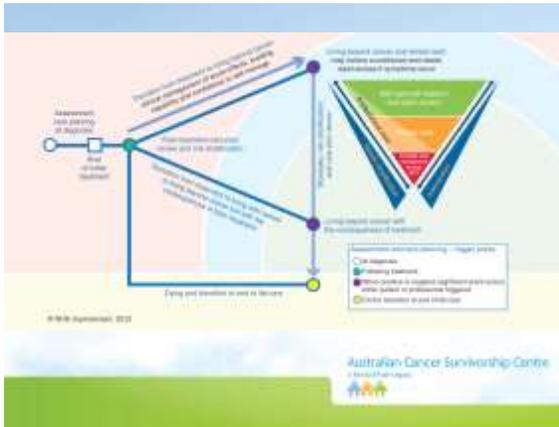
- 230 responses (from 5090)
- Suggested interventions
  - Equipment provision
  - Energy conservation
  - Pressure care
- Barriers
  - Lack of funding
  - Lack of recognition of role



## Comments

- Possible need for further training
  - Cancer Australia site
- Care should be multidisciplinary
- Need for effective care coordination
- Who is best placed to coordinate care?
- Funding models to support flexible care delivery





## Comments

- Patients want information to self-manage
- Patients want to be empowered
- What is the best model to use?
- How to scale?

### Abstract

**Coping Together & Self-Management Intervention to Address the Psychosocial Needs of Couples Affected by Cancer**

**Jeffrey Jackson<sup>1</sup>, Alf King<sup>2</sup>, Sylvia Lambert<sup>3</sup>, Patrick Mulvihill<sup>4</sup>, Jane Turner<sup>5</sup>, Karen Raper<sup>6</sup>, Catherine Mihalopoulos<sup>7</sup>**

1. University of New South Wales/Ingham Institute, LIVERPOOL, NSW, Australia
2. University of New South Wales/Ingham Institute, LIVERPOOL, NSW, Australia
3. Monash University, Australia
4. University of Newcastle, Newcastle
5. University of Queensland, Brisbane
6. University of Newcastle, Newcastle
7. Deakin University, Burwood, Victoria

**Background:** Patients and partners report similar reactions to a cancer diagnosis, including fear, anxiety and distress, with a stable severity reporting sustained reactions for extended time periods. Such reactions may mutually impact on the wellbeing of both members of the dyad with findings indicating that partner and partner reactions mutually influence how the other person adjusts. **Aims:** a) to identify core concerns, information priorities, information satisfaction, stressors, appraisal (stress) and coping; b) to develop a self-management intervention to address adjustment and coping in couples adjusting to a cancer diagnosis; and c) to develop a self-management intervention to address adjustment and coping in couples adjusting to a cancer diagnosis.

**Results:** Patients and partners identified their main concerns as psychosocial rather than medical in nature. Compared to patients, partners reported receiving significantly less information on psychosocial matters, e.g. support services (p = .001) and self-care (p = .001), and were less satisfied with information received (p = 0.002), potentially because it didn't address their core concerns and was not targeted specifically to partners.

To address such issues we developed Coping Together, a novel self-management coping skills intervention targeting couples. Its primary focus is on the development of practical coping behaviours. Coping Together addresses current gaps in supportive care resources, focusing on psychosocial issues such as the impact of diagnosis on the couple's relationship and dealing with emotional reactions. Initial pilot testing (n=42 couples) demonstrated a trend (p=0.05) towards improvements in patient distress and stress appraisal, lowered partner stress, caregiver burden and financial strain, and improved stress appraisal and sustained coping.

**Conclusions:** Coping Together potentially addresses the psychosocial needs of couples dealing with cancer in a way that is feasible, acceptable and sustainable due to its self-directed nature. There is opportunity for Coping Together to support vulnerable couples, particularly those living in rural areas or with limited access to supportive care services.

## Abstract

- Carers have many similar reactions and needs
- Interactions (patient / carer) are important
- Development of practical coping behaviours
- Pilot suggests improvements

## Comments

- Need to consider carers / family members
- Need to tailor / target to unmet needs
- ? Target those with greater unmet need / potential for benefit
- How to scale?
- Cost?

## Fit to Thrive: A Specialised Exercise Program to support patients with a haematological malignancy.

**Ma'ayana Berger<sup>1</sup>**  
<sup>1</sup> Leukemia Foundation of Queensland, Stater Park, QLD, Australia  
 Research is increasingly showing that physical activity for cancer patients before, during, and post treatment can improve muscle endurance, decrease symptoms of fatigue, improve balance and flexibility, increase muscle mass, and improve quality of life. A collaborative approach between the Leukemia Foundation of Queensland and Aquatic Fitness and Rehabilitation led to the development of this 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 free specialised exercise program to support patients from diagnosis, through treatment and beyond. This program aims to assist patients both individually and in a group setting. This allows them to meet their individual goals, enhance their quality of life, and provides them with the best practice in patient care. It also provides valuable data for research into the benefits of exercise for this patient group. The initial intake of the program recruited a total of 50 participants (5 groups of 10 participants). The participants ranged in age from 20 – 75 years old and had been diagnosed with a haematological malignancy. Participants were assessed against their own individual responses and improvements. Clinically relevant subjective and objective measures were recorded to assess the program's needs. Fit to Thrive has been a powerfully positive experience for the first cohort of participants. Based on the accumulated data and anecdotal feedback, the program has been able to deliver an individualised approach to rehabilitation in a group setting with dramatic impacts on functional strength, endurance, reducing fatigue and improved psycho-social measures. Every patient improved on every quantitative measure of the study. While the data is yet to be statistically analysed, it does appear to deliver as a pilot program, in showing positive trends.



## Comments

- Need to promote the broad benefits of healthy lifestyle
- Link survivors with community-based services
- Effective engagement with NGOs
  - VCSP pilots linked with YMCA gyms, Cancer Council
- Healthy Living after Cancer

## Conclusions

- Understand experience, needs
- How to meet needs?
  - Draw on existing information, resources
  - Self management
- What models of care?
  - Who is involved?
    - Primary care, cancer specialists
    - Medical, nursing, allied health

## Conclusions

- Data / measurement
- Research
  - Lots of questions
  - Patient focussed
  - Need funding
- Advocacy
  - Empowered survivors

