

# What matters to cancer survivors? From awareness to advocacy

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cancer voices sa

RAISING A VOICE FOR THOSE AFFECTED BY  
CANCER



# Acknowledgments

- I would like to acknowledge the Kaurna people who are the traditional custodians of this land.
- I would like to pay respect to the elders past and present of the Kaurna nation and extend that respect to other Aboriginal people present.



I would also like to pay respect to all those who didn't make it and to my mother, who died of bowel cancer, aged 54



# Own story

- Diagnosed with breast cancer in 2003
- Recent French migrant in Australia
  - No family network, limited friend network
- 5-year old daughter
  - How to communicate? What to share?
- Single income earner, no sick leave
  - Need to continue working
- Health professional: drug information pharmacist, academic researcher on quality use of medicines
  - ‘Too’ aware of potential severe adverse effects...feeling about ‘an impending execution’ when chemotherapy started...

Mummy,  
where did  
they put  
your breast?



Fear for my daughter, fear of dying far from my family and friends, fear of treatments



# Own story

- Health activist
  - access to essential medicines in developing countries (Health Action International),
  - action against misleading information on medicines by drug companies (Healthy Skepticism)
  - A bit of a warrior...
- Excellent health acute care team
  - thanks Bogda!



# Own story

- Post-acute care
  - chemofog
  - medicalisation of grief and anxiety
  - lack of awareness of late adverse effects of endocrine therapy by GPs (ignorance, negligence)
  - a few recurrence scares....
  - reading, painting, gardening, volunteering, networking...and Cancer Voices SA





# Multiple stories

- Acknowledgment of different experiences depending on socio-economic and cultural context and personal experiences
- Informed by personal illness narratives, cancer conversations, blogs, interviews, surveys, studies
- The hero of 'Cancer ward', a novel by the Russian Nobel prize winner Solzhenitsyn (1967), Kostoglotov, a Russian dissident who was in a labor camp during the Stalinist Soviet Union, was one of the first cancer patient advocates for patient-centered care
  - Right to know
  - Right to be involved in decisions
  - Regain control!





# What is to be a cancer survivor?

- No consensus definition, myriad of meanings for different individuals (Pam McGrath, 2012)
- ‘Enthusiastic embrace’: part of their sense of self
- ‘Active dislike’
  - Assumes a similarity among people who have different experiences of cancer
  - Assets an imminent connection between us and our disease
  - ‘there’s a blame game going on: those who survive did something heroic; those who don’t survive just weren’t tough enough’ (blog Calling the shots)
- Conflicting thoughts
  - ‘Don’t give up heroic struggle’
  - ‘Acceptance of finitude of life and death’



# What is to be a cancer survivor?

- Term to stay, useful for advocates, consumers, health care providers, researchers
- 'Concept of how the experience of cancer might affect someone holistically and evolve over time' (Fitzhugh Mullan, *Seasons of survival: reflections of a physician with cancer* )
- 'a life-changing experience, with a duality of positive and negative aspects unique to the individual experience but with universality' (Natalie Doyle, *Cancer survivorship: evolutionary concept analysis*)
  - Cancer leads to fundamental changes in identity and reappraisal of values and beliefs
  - Cancer immediately focuses the patient to think about death
- Dynamic dimension
  - Post acute treatment, routine life, recurrence or pseudo-recurrence episodes, awareness of late adverse effects, awareness of how your life has been changed (voluntarily or not)



# What matters to a cancer survivor?

- Metaphor of the war (Susan Sontag)
  - ‘I don’t call myself a survivor, I call myself a warrior’  
(Sandra, Aboriginal woman, Canada)
- Metaphor of the fairground (Meg Rynderman, ACSC volunteer)
  - ‘a roller coaster – unexpected highs and lows, slow painful climbs, rapid descents with no guarantee of what was to present around the next bend’
  - ‘a ticket to the merry-go-round. Oncologists finish treatment and follow-ups and wave you goodbye to get on with the rest of your life. GP’s watch nervously, never sure whether symptoms are related, should be tested or scanned, quietly suspecting something sinister; families observe, worried that you might fall off the pretty merry-go-round horse of health’.



# Psychological, emotional and spiritual challenges

- ‘accepting the changes, understanding the new normal, incorporating the scars, the loss of function, and the limits and about waking up each morning to face a new day’ (Meg Rynderman, ACSC volunteer).
- Fear of recurrence, of death, of new treatments
  - Thin line between being too anxious or neglectful (previous common experience of having been caught by surprise!)
- Psychology of survivorship and how to cope (or how to regain control): many different ways



# Psychological, emotional and spiritual challenges

- Psychological 'support' by specialised health professionals
  - Can be great!
  - Risk of overmedicalisation of 'normal' sadness, grief and fear
    - Beyondblue leaflet 'depression and breast cancer'
    - *'depression is more than just a low mood, it is a serious illness' and "up to 50 per cent of women with early breast cancer may experience depression and/or anxiety in the year after diagnosis"*.
- Emotional support: role of all staff
  - 'Remember that, even though this is the millionth time you have seen and done this, it is the patient's strange, unknown, and even frightening first time' (Tanya Hall, *More than the sum of our parts*)



# Psychological, emotional and spiritual challenges

- ‘Public and private discourses shape the manner in which women experience breast cancer, including their strategies for coping with negative feelings and making sense of illness’ (Agnes Vitry, *The imperative of happiness for women living with breast cancer*)
- Important role for this conference to promote new, innovative discourses about cancer survivorship and the collaboration required between all stakeholders in facing cancer survivorship challenges



# Psychological, emotional and spiritual challenges

- Illness narratives, blogging, support groups
- Social and family support, networking, reading, physical activity, riding, meditation, complementary medicines, massage, art therapy...
- Awareness, information, support and advocacy work in 'holistic' organisations such as Cancer Voices SA





# Psychological, emotional and spiritual challenges

- Challenge of integrating medical, psychological and social services offered by numerous public, private and non-profit organisations and individuals



# Late adverse effects of treatments

- Very limited research on this topic (short trials, lack of follow-up of adult cancer survivors)
  - More other chronic diseases in cancer survivors
  - Poorer health and well-being
  - Systemic adverse effects, fatigue
  - Chemotherapy and cognitive effects
    - Cognitive deficits still marked twenty years after chemotherapy for breast cancer compared to women who did not receive a chemotherapy
  - Menopausal symptoms more severe when treatment-induced
  - Urogenital adverse effects
  - Sexual well-being
  - Bone adverse effects
  - Cardiac adverse effects
  - Gastrointestinal adverse effects
  - CNS complications
  - Radiotherapy and surgery specific complications



# Late adverse effects of treatments

- Identification
  - Limited data on characteristics of adverse effects
    - Frequency, intensity, risk factors, duration
  - Lack of knowledge and awareness of adverse effects of both hospital and primary care doctors
  - Little research on usefulness of screening



# Late adverse effects of treatments

- Management
  - Limited research on efficacy and safety of management options: palliation?
  - Medical judgment may be biased in favour of benefits of medicines and downplaying the impact of adverse effects on quality of life
    - 'Physicians should be aware of these [online] discussions and guide patients to effectively manage side effects of drugs and promote optimal adherence' (Jun Mao, *Online discussion of drug side effects and discontinuation among breast cancer survivors*)'
    - Sometimes, there is no effective and/or safe proven treatments of debilitating adverse effects, stopping the harmful therapy may be the less worst option for maintaining the quality of life



# Late adverse effects of treatments

- Lack of knowledge and consideration for long-term adverse effects may affect the appraisal of the risk/benefit balance of cancer treatments
  - Risk-adapted therapy for children
  - and adults too!



# Quality of health care

- Improvement over time for acute care management
  - Better treatments
  - Better collaborative multidisciplinary care, cancer nurses
  - Better communication of test results
  - Better discussion around treatments and outcomes
  - Better information resources
  - Cancer support groups and organisations
  - etc



# Quality of health care

- Major gaps in follow-up care
  - Focus on detection of recurrence
  - Patient-provider communication
    - Information about risk to benefit ratios of treatments, shared decision making
  - Ignorance, lack of or mis-management of well-known adverse effects or less well-known adverse effects
  - Lack of communication between acute care healthcare team and GPs
  - Where do we go?





# Quality of health care

- Cancer survivor care plans
  - Summary of cancer treatments
  - Ongoing care directions
  - Specific recommendations
- Cancer survivor defined care pathways
  - Coordination of care, communication between hospital and primary care health professionals
- Cancer survivor specific services
  - Lymphoedema clinics, rehabilitation centers, fitness centers
- Information resources/training for consumers and health professionals



# Social care

- Return to work
  - Work discrimination
- Financial concerns
- Impact on family, caregivers, relationships
- Diversity of support options for individuals and families



# Social care

- Specific needs of groups most at risk of poorer survivorship: Aboriginal and Torres Strait Islanders, cultural and linguistically diverse populations, children, rural inhabitants
- Integration of psycho-social care delivered by non-profit organisations and mainstream socio-medical services



# Recent progress

- Several initiatives in different countries
  - American Society of Clinical Oncology Statement: achieving high-quality cancer survivorship care
  - Livestrong Foundation programmes
  - The United Kingdom National Cancer Survivorship Initiative
- In Australia
  - Inaugural national conference
  - Research increasing on cancer survivor needs, best models of care
  - Active cancer consumer organisations
  - Soon...the Flinders Charter of Cancer Survivorship
  - And much more!



# Thanks for your attention!

