



## “More than just telling my story” when *cancer survivors become teachers*.

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Involvement of .... patients, carers and service users is .....patchy, particularly in medical education,

There is strong evidence that patient/user involvement has short-term benefits for all involved, ..... across a wide range of domains, such as **knowledge, skills, attitudes, behaviours**.

**Longer term, there has been little evaluation** on whether patient/user involvement has an effect on **the behaviour or practice of health professionals or on health outcomes**.

### patients invited into the classroom to share experiences of chronic illness.

Both students and consumers reported benefits from this model:

- perceived **relevance**;
- enhanced **understanding** of patients' perspectives;
- enhanced **communication skills**;
- increased **confidence** talking to patients;
- learning in a non-threatening environment.

- 'Patient narrative interventions' are reported to
- deepen **understanding** of the experience of **disease and**
- teach about the impact on **social, psychological and socioeconomic status, lifestyle and well-being aspects**.



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### Aims of survivors as teachers:

improve quality of care in the health system by enhancing communication and understanding.

increase health professionals understanding about the all-encompassing impact cancer can have on individuals and their family, along with the toll on their emotional, physical, practical, and financial lives ....

**and outline the positives, 'highs'** as well as the lows after cancer diagnosis..... **the spectrum of illness and wellness**

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## teaching methodology

- **small group, interactive sessions** designed to provide an intimate learning experience,
- **led by cancer survivors** (volunteer speakers), who shared their personal insights & experiences of cancer, & tips for good communication,
- 'team' approach, **one main speaker, one or two Cancer Voices as support to facilitate and 'chip-in' their additional viewpoints to illustrate similarity or differences in experience or opinions.**
- **Debriefing and feedback from speakers** and 'team' afterwards,
- evaluation from students or student supervisors
- speakers with a diversity of experiences as a patient or carer, different cancer types and stage, cultural, social, economic, age, gender, sexuality and urban/rural background.

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## 'Survivors as teachers' - sessions held

year	total number of students, nurses etc attended	group sessions
2012	90 med students 3 <sup>rd</sup> yr (8 students/group) 8 oncology grad dip nurses	11 tutorials 1 group
2013	100 med students 3 <sup>rd</sup> yr (8 students/group) 3 oncology grad dip nurses	12 tutorials 1 group
2014	120 med students 3 <sup>rd</sup> yr (8 students/group) 12 oncology grad dip nurses 40 supportive & palliative care nursing students 20 pharmacy students 3 <sup>rd</sup> yr 8 SA PoCoG interest group researchers 9 rural oncology centre nurses (telemed)	15 tutorials 1 group 2 groups 1 group 1 group 1 group
2015	150 med students 3 <sup>rd</sup> yr (12 students/group) 9 oncology grad dip nurses 40 supportive & palliative care nursing students	13 tutorials 1 group 2 groups



### speakers touched on:

- **decision-making dilemmas**
- the '**chemistry**' between patients and clinicians is important
- patients and carers **need information** to be provided
  - good sources of information and resources
- good and timely **communication** for patients and loved ones
- patients and doctors risk making **assumptions**
- patients don't know how the 'system works' or how health care professionals communicate
- **humour** - an important component of healing
- challenges of coping with anxiety, anger, depression &/or fear
- managing at home after treatment
- managing work &/or financial worries
- lifestyle and self-care issues

Practical presentation tips eg \*use visual aids -MRI, CT scans, radiation mask

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## Survivors evaluation

- rewarding and, at times, cathartic
- 'giving back' to help future cancer survivors.
- support through 'team' approach contributed to increased confidence and satisfaction as 'teachers',
  - increased awareness of the diversity of other cancer survivor experiences
  - see one, before you do one
    - very valuable – what to expect from students, how to plan structure of tutorial presentation
- **promote culture of mutual respect**; patient-centred-care focus
- convey that **clinicians words can have such a lasting impact**



## student evaluation & feedback

1 page Reflective piece

- What surprised you
- What feelings
- How might it change your practice?

Acknowledgement:

Thank you Dr Jo Thomas, Adelaide Uni Medical School, for student evaluation results



## What surprised you

- not all about mortality
- difficulties in diagnosis
- Different type of disease than expected
- how accepting the person was
- The lack of concern for patients agenda
- How positive the person is

## Reflective pieces

Majority very thoughtful

- Impacts:
  - Financial
  - Emotional
  - Professional
  - Relationships
  - Sexual
  - Infertility
  - stigma



## Change in your practice?

- Communication issues- to patient , to other clinicians
- Choice of words
- Talk to family as well
- Look beyond the medical
- Awareness of values and beliefs of the patient
- Give decision making to the patient
- Respect and support
- Positive approach, convey hope



### Extracts from student feedback:

“she gave us a checklist of qualities she found particularly striking in a health professional. The main theme I absorbed was to **treat a patient as a real person, rather than a case to solve.**”

“An amazing and intimate insight into the life of a family living with cancer. Interesting factors that I would not have otherwise learned/heard about”

“Makes you rethink about how you will talk to and listen to patients when you are in the hospital. Opens your eyes to the way patients want to be treated and how much they want from the health system”



### where to from here?

Survivors' knowledge and insights wrought from their cancer experience(s) .....richly contribute to the classroom and in-service curriculum for health professionals.

Positive evaluation from student feedback and reflective writing exercises has resulted in these interactive 'Cancer Survivors as Teachers' tutorials now being firmly embedded in one medical school curriculum.

Long term impact on clinical practice and patient care needs evaluation.



### THANK YOU, THANK YOU

to the team of volunteer speakers and support people who have contributed to this.

If you are interested to become involved  
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