

Survivors in the survivorship equation: survivor evidence + survivor views of best practice = better outcomes

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Introduction

Can **better outcomes** be achieved when **survivors experiences and 'best practice' views** are systematically embedded **into health professionals education**?^{1,2,3}

Survivors as Teachers[®] is a survivor-led program, co-designed and established in 2012 by **Cancer Voices SA**, an independent, survivor-led advocacy organisation raising a voice for people affected by cancer^{4,5}.

The Survivors as Teachers program aims to deepen the **knowledge, understanding and attitudes** of students about the impacts and challenges faced by people living with a cancer diagnosis, their families and support networks. The program involves a diverse range of cancer survivors (age, culture, gender, demographic, geographic, public/private, cancer types and stages).

This overview and analysis of the *Survivors as Teachers* program accumulated over the period 2012 - 2017 reviews learning outcomes achieved through this innovative education program for medical, nursing and allied health students in South Australia's three main universities (Adelaide University, Flinders University and University of South Australia).

Methods



The **Survivors as Teachers** program is led, organised and facilitated by cancer survivors, in partnership with University course coordinators.

Sessions are presented by cancer survivors, facilitators and support people who all have a lived experience of cancer. Facilitators and support people assist in introducing the sessions, supporting the presenters as needed during the session, particularly their emotional needs, suggest resources, set up the learning environment, and build connections through questions and discussion.

- Over the **6 year period 2012 – 2017** our **Survivors as Teachers** program has involved
- **1350 students** (600 3rd yr medical students, 300 1st yr nursing students, 300 2nd yr health science students, 120 3rd yr nursing students, 30 oncology grad-diploma nurses, 20 3rd yr pharmacy students, 3 psychology masters students)
 - **100 interactive tutorial sessions**
 - **50 cancer survivors covering 200 session attendances** – as speakers, facilitators and/or extras providing diverse experiences eg. as patient, carer, couples, parents; public, private, urban, rural services; brain, breast, cervical, colorectal, leukaemia, lymphoma, melanoma, mesothelioma, peritoneal, prostate, sarcoma, stomach and testicular cancer types.

Survivors as Teachers sessions:

- **Small groups, panel discussions and question and answer forums are the key teaching methods** used, with small groups ideally seated in a circle formation. **The method enables interaction between the students presenters, facilitators and support people.**
 - Program methodology is based on adult learning principles⁶ and continues to evolve in response to feedback received from students, presenters and university course coordinators.
 - Survivors presenting their lived experience are self selected volunteers who are supported by other survivor presenters. They are given the opportunity to participate in a session before their first presentation and are provided with tips for structuring their presentations and interacting with adult learners. First and foremost it is a **flexible structure with presenters given license to tell their story** and to enable interaction with the students. Presentation methods have included use of powerpoint, photos, handouts, videos, personal items such as quilts and recipes, and medical resources eg., radiation mask, proton therapy mould.
 - Sessions are **one hour duration** and tailored to meet the needs of the student group.
- In each university **individual course coordinators have been critical** to commit tutorial timeslots, identifying the appropriate timing for this element of student learning, and to ensure sustainability of the program.

Data collection methods:

Data collected includes reflections about the program from individuals group debriefs, targeted surveys, post session feedback forms, emails, and course coordinator feedback to presenters.

- Reflection and capturing the learning is an integral component of the program's methodology.
- **Students must write a one page reflection based on three key questions**, debrief with fellow students and course tutor and/or complete survey questions.
 - **Presenters are involved in debrief sessions** which serve to capture their learning and are also used to address emotions and memories raised during what is often the first time presenters have compiled and told their story in public.
 - **Facilitators collate learnings and feedback from presenters**, both in terms of the teaching experience and the content of their story where it highlights advocacy issues and insights relevant for Cancer Voices consumer representatives.
 - **Course coordinators meet with facilitators and presenters** each year to share feedback, discuss and refine the format or any supporting teaching elements needed.

A **thematic analysis of six years of data** obtained through the *Survivors as Teachers* program has been undertaken to ascertain the **impact of the program on students, presenters, facilitators, course tutors, and opportunities for improving the program.**



Results

Evidence of impact on students:

Students gain understanding from hearing *the lived experience of patients*:

- Students learn or have reinforced **the importance of treating patients as a whole person, not just as a diagnosis.**
"It provided me with useful tips. The reflective writing process assisted in crystallising my thoughts about the session and made me think about how a patient feels not just the diagnosis. It gives insight into emotions and experiences."
- Students note that while it can be **overwhelming, confronting and uncomfortable at times** to hear the stories of the cancer survivors, the program is structured to support their learning in a real way that highlights good practice alongside any bad examples of health professional practice and the health system as a whole.
"It makes you rethink about how you will talk to and listen to patients when you are in the hospital. It opens your eyes to the way patients want to be treated and how much they want from the health system."
- Students are **surprised by the depth of knowledge cancer survivors have of their condition** and our thoughtful tips for health professional practice. They are grateful for the generosity of presenters who offer what they variously describe as a **unique, informative, moving and powerful window** into the experience of being diagnosed with cancer.
- Prior to experiencing the program, most students have not fully considered the life changing impact of a cancer diagnosis, particularly the impact of negative experiences, such as poor service and sub-standard communication.
- Students also noted that **they hadn't thought about the complex needs of many people diagnosed with cancer**, for example the variation in individual response to the emotional, physical and practical implications of a cancer diagnosis. They further highlight the need to be cognisant of the importance of being empathetic and caring, not just focusing on the clinical and to think more widely than the medical model.
- Evidence from the multiple sessions has been accumulated, providing deep insight into the **immediate impact of the presenters stories on the understanding, knowledge and attitudes** of the students. It indicates the rich source of lived experience makes them think about a **broad range of aspects important for being a health professional.**
- For many it **affirms their choice of career**, crystallising theory and practice at a critical learning timepoint
- The sessions also have the effect of **challenging assumptions** and current thinking with **good tips on how clinicians can improve their approach to people and families dealing with cancer**, especially the **importance of good doctor-patient communication** and the importance of the **social, psychological and economic impacts of cancer**, both critical in **reducing misunderstandings and patient distress.**
- Student feedback also highlights their learning about **the importance of effective communication between clinicians and health professionals** and the benefits of a **multi-disciplinary approach** that centralises the importance of the patient.

Conclusions

There is clear evidence that the impact of the **Survivors as Teachers** program, based on the personal accounts of cancer survivors, is powerful and encourages **deeper student understanding of, and empathy** for, how patients experience disease. It provides a **bridge between students' academic studies and practice** and assists in **challenging assumptions** and building new ways of thinking about their role as a health professional as well as providing tips for how they could **better meet the needs and expectations of patients.**



Students consistently indicate that they are deeply affected by the presenter's stories and a **transformative learning process** takes place within the program.

Information from each session over the past six years provides Cancer Voices SA with accumulated evidence of the benefits, challenges and outcomes of the *Survivors as Teachers* program. This has assisted in **driving program improvements** and ensuring the program remains **relevant and targeted to the learning needs** of the students involved and **adds value** to the overall curriculum. Evidence indicates the *Survivors as Teachers* initiative is good for patients, health professionals in training, and has the potential to benefit the continuing medical education of health professionals.

Ongoing evaluation of this model suggests this is a **best practice model for improving student learning outcomes** and that this can be **translated into improving the practice of health professionals and the health system generally**, as well as improving the experience and outcomes for people diagnosed with cancer. Further evidence from the perspectives of the cancer survivor presenters, facilitators and university staff to supplement the student evaluation is forthcoming in a paper titled **Survivors as Teachers – the South Australian Experience.**

Cancer Voices South Australia's **Survivors as Teachers** program is an **innovative teaching and learning approach**, increasingly being embedded within health and medical training programs of South Australian universities.

References

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