

Highlights

Raising the Awareness of Undergraduate Nurses to the Psychosocial Impact of Living with Cancer: A Consumer Engagement in Teaching Initiative

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ABSTRACT

This article reflects on the development and implementation of a consumer engagement in teaching initiative by the authors. The authors highlight the challenges of engaging undergraduate nursing students on the psychosocial aspects of living with cancer and other chronic illnesses when students have very limited personal and professional experiences to draw on. The authors discuss how they have responded to these challenges by integrating the voices of consumers into their classrooms. Speakers from consumer advocacy organization, Cancer Voices SA, participated in a series of tutorials in a 1st year topic in the Undergraduate Nursing Program at the School of Nursing and Midwifery, Flinders University. Student feedback from the implementation of the initiative indicated that students found consumers' stories and experiences of living with cancer, "moving and powerful" and that they encouraged students to question their assumptions about the psychosocial impacts of cancer on individuals

and families. The importance of good communication in reducing patient distress was identified by students as an important element of consumers' experiences of the health care system as was the need for transparency and information sharing between health care providers across the health care system. For many students, consumers' stories and experiences had reinforced students' commitment to studying nursing and pursuing a career in nursing. The article concludes that involving consumers in the education of health care professionals encourages a much deeper understanding of and empathy for how patients experience disease, which is integral to the provision of patient-centered and holistic care.

Key words: Cancer, chronic illness, consumers, patient-centered care, psycho-social impact, teaching, undergraduate nursing students

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Introduction

As coordinators and lecturers of large undergraduate nursing topics (At Flinders University, the term “Topic” is used in reference to a course or subject of study), it is often difficult in both classroom and online forums to engage students in real-world contexts and situations that can enhance their learning. There is little doubt that the technological age has enabled us to create very effective teaching tools that connect students to an array of hypothetical cases, patients, diagnoses, illnesses, and health care environments.^[1] In addition, placements allow students to directly participate in real-world clinical environments. However, these modes of teaching still have their shortcomings. We know from our own teaching experiences that students’ learning from online and simulated environments still requires knowledgeable facilitation by teaching staff both in the classroom and online and in many instances, this mode of learning tends to be geared toward the study of the biomedical rather than the psychosocial aspects of illness and health care. Similarly, clinical placements, which are constrained by time and supervision requirements, do not always allow students to focus on or fully appreciate the psychosocial contexts of illness and treatment and its impact on the patient. More importantly, students are often required to participate in clinical placements following their study of theory in the classroom, making it difficult for students to grasp the complexities of concepts they are learning without yet having the clinical experience to back it up. Hence, we are often confronted with questions such as: “How can I facilitate students’ understandings of the day to day “lived experience” of patients and their families?” and “How can I make concepts like ‘empathy’ real for students?” When their only experience with patients has been in a “virtual” world or in a brief acute, hospital stay.

This is a particular problem when teaching topics relating to the psychosocial perspectives of health and illness because understanding the “inner worlds” and social contexts of patients and their families is difficult enough face-to-face let alone in the often sheltered environment of the classroom. Two questions were posed by academic staff at Flinders University:

- a. How can students be taught the nuances important to patient-centered care, such as empathy, sensitivity, and emotional responsiveness? And
- b. What community-based resources can assist students to learn these important aspects of care provision?

Development and Planning

It was these questions and our struggle to address them that led us to begin conversing with a range of consumer organizations, one of which was Cancer Voices SA. Cancer Voices SA is a 100% volunteer consumer advocacy group that represents the views of South Australians whose lives

have been affected by cancer. It focuses on “raising a voice for those affected by cancer” through advocacy, involvement, awareness, and information. Its members have a wealth of experience in speaking to and educating the broader community about being diagnosed with and living with cancer as well as the challenges of engaging with the health care system as a “cancer patient.” In addition, Cancer Voices SA has an established track record of embedding consumer experiences in university programs for medical students.

It was during our conversations with Cancer Voices SA and other consumer advocacy organizations that we decided to implement a “consumer engagement in teaching” initiative in our curriculum for the first time in 2015. We discussed the many formats that implementing such an initiative might take, for example, asking consumers to speak to the whole student cohort in a lecture/workshop format or organizing a symposium at which consumers could speak to students in a number of sessions across 1 or 2 days. Given the very large number of students in the Flinders University, School of Nursing and Midwifery, Undergraduate Nursing Program and the many and varied commitments of students, there was a concern these formats would either not attract students or would not engage them in a meaningful way. Hence, we decided the most effective format would involve:

- Consumers speaking at students’ tutorials or class sessions for the 1st hour of the 2 hour tutorial class.
- Tutorial facilitators using the second remaining hour to build on the learning and insights provided by the speaker and to give students an opportunity to debrief and discuss their responses to what they had heard from the speaker.

Consideration was also given to which topic in the Undergraduate Nursing Program would be the best fit for and derive the most benefit from consumers’ experiences. The focus for Cancer Voices SA speakers was to present the experience of cancer as a chronic disease and the ongoing evolving psychosocial impact on the individual and their families. Hence, it was almost immediately apparent the 1st year undergraduate nursing topic — Psychosocial Perspectives of Health Care — would be ideal for a number of reasons:

- The topic is run in the 1st year of the Undergraduate Nursing Program, which would allow for consumer experiences to be introduced to students in the formative years of their study, which is important for their socialization into the nursing profession.
- The topic has an approximate enrollment of 500 students per semester, which would help to ensure that consumer experiences would have as broad a reach across the student cohort as possible.
- The topic was considered to have the most need for an understanding of patients’ and their families’ experiences of living with cancer. The topic introduces

students to the psychological and sociological factors that influence health care and explores theories that may assist understanding of these factors.

- In the 8th week of this topic, students focus their attention on living with a chronic illness and are required to draw on the psychological and sociological concepts they have learned in the previous weeks of the topic to understand the experiences of those living with and managing a range of chronic conditions such as cancer, HIV, physical disability, and mental illness.
- In previous years students did not seem to gain much from research articles about patients' experiences, even those taking a phenomenological approach, and class activities were limited by the shortage of personal and professional experiences of living with a chronic condition. Hence, it was agreed that this topic was most likely to benefit from the input of "real" consumers' experiences of living with cancer.

During the implementation of this consumer engagement in teaching initiative, we were keen to seek students' feedback. We did this by asking students to provide a brief written response to the following question.

After listening to (name of the consumer), what aspects of her/his story had the biggest impact on you?

- As an individual.
- As a student, studying to be a Registered Nurse.

This question was chosen to elicit both personal and professional perspectives as each becomes interwoven with the other in the formation of a professional identity.^[2] This feedback was vital to our capacity to reflect on the strengths and weaknesses of the initiative from a pedagogical perspective. It also enabled us to identify the ways that consumer involvement in the classroom can enhance students' and tutorial facilitators' understandings of the psychosocial aspects of living with cancer as well as what patient-centered care looks like from the perspective of consumers. The remainder of this article reflects on key aspects of students' feedback.

Evaluation

First, students' feedback was overwhelmingly positive. In fact, there was no negative feedback provided about the initiative. Students found the speakers to be informative and engaging and their stories and personal experiences of living with cancer, "moving" and "powerful." While many students felt overwhelmed by the stories they heard, many praised the bravery and courage of the speakers in being able to provide such a personal perspective.

"I was overwhelmed, in both a positive and confronting way today, with the speaker who attended our session and

spoke of her cancer experience and treatment. As a student, to gain the patient perspective was immensely interesting and insightful. I am very motivated to say how beneficial the experience was personally and as a student."

Second, students' feedback showed speakers' stories and experiences had given them much needed insight into the journey of cancer patients from initial diagnosis and treatment through to the readjustments they have had to make to their lives in the short- and long-term. Students acknowledged the difficulty of being able to fully understand the psychological reactions from patients affected by cancer without having been through such an experience themselves and that the speakers had assisted them to have empathy for what patients with cancer may be feeling and thinking. Students highlighted the relevance and importance of these insights for their nursing practice, particularly in terms of how they could assist them to better meet the needs and expectations of their patients in the future.

"Sometimes it's hard to fully understand the psychological reactions from patients with illness because we don't experience what they experience. Those emotions and feelings are impossible to understand by imagination. I recognize this speaker will help me and other students to have empathy with what the patient feels and perceives from their point of view. Also thinking how can we be a better nurse to meet the patient's expectations. That's going to be very relevant and have an impact in the future."

Third, students' feedback showed speakers' stories and experiences had highlighted the many ways that patients manage and cope with cancer, including how misconceptions and stigma can further compound the psychosocial effects of illness. It was clear from students' feedback that the speakers had encouraged students to question their assumptions about how cancer impacts on social, cultural, psychological, socioeconomic status, lifestyle, and well-being aspects of people's lives, allowing students to form more accurate, and nuanced understandings of the cancer experience. For many students, the speakers' stories had turned their understandings of the cancer experience from a mechanical one to a more human one in which they could more fully appreciate the strengths and coping abilities that patients bring to the cancer experience.

"The speaker told us about how she had cancer as a teenager. Her story was very sad but there was no self-pity in it, just her courage about how she got through it with the help of her family and friends and how she has coped over the years with the changes to her body."

Fourth, speakers' stories and experiences of the health care system had highlighted for students the importance of good communication between patients and health care

providers; in particular, the stories showed how a lack of understanding, borne out of poor communication, can exacerbate patients' distress as well as how transparency and information sharing between health care providers across the health care system can prevent misunderstandings, promote the trust of the patient, and enhance their well-being. For many students, the speakers' experiences of their treatment and hospital stays emphasized the enormous impact that health care professionals can have on the patients' emotional and psychological well-being. For some students, this was a particularly sobering insight as they had not previously grasped the extent and power of the nurse's role in providing emotional support to patients at their most vulnerable.

"This afternoon we had a guest speaker sharing her story of cancer, how she felt in the life changing moment, what she experienced in the hospital from a patient's point of view, and what character she considers a nurse should have. It was very touching to listen to her story. I am so glad that she came here to speak in our class."

Fifth, and perhaps most unexpectedly, was that for many students, the speakers' stories and experiences had reinforced students' commitment to studying nursing and pursuing a career in nursing. Students come into nursing for many and varied reasons, and it is not uncommon for some of them to reveal to us that their studies are not what they had expected and that they have found it difficult to reconcile what they are learning with how they had perceived and understood nursing. For many students, the speakers' stories and experiences provided a much needed bridge between the students' academic studies and nursing practice. It also reinforced for them the importance of empathy, caring, tacit knowledge, and intuition in the role of the nurse — aspects that attracted them to nursing in the first place — but which are often overshadowed in the curriculum by the very real need for nurses to gain the hard knowledge that is a requirement of their practice.

"This week's class was the best I have had. The guest speaker was amazing and I came away with the reassurance that I am most certainly in the right course. Thank you for organizing such a brilliant experience."

Conclusion

In order to build a quality health care workforce at the university level, educators must encourage students to think more widely than the medical model. That is, students need to be supported to view the patient as a whole person — with memories, feelings and emotions and with connections to place, culture, and family — rather than as just a patient requiring treatment of their disease. While literature pertaining to the impact of consumer involvement in the education of health professionals is small, there is some evidence to indicate that it may have a positive effect on students' interpersonal skills and empathic understanding; skills that patients have been shown to place high value.^[3] The feedback from our own students has shown that the integration of consumers' voices in the classroom can enhance students' understanding and recognition of the psychosocial impact of chronic illness and the factors that consumers identify as important in the care they receive. In this way, students are given the opportunity to develop a much deeper understanding of and empathy for how patients experience disease, which is integral to the provision of patient-centered and holistic care.

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Conflicts of interest

There are no conflicts of interest.

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