



EDCAN CONSUMER FORUM FACT SHEET - 23RD MAY 2007

Background

The EdCaN project is one of Cancer Australia's initiatives to improve outcomes for people affected by cancer. The aim of the project is to develop a national framework to address the nursing workforce caring for people affected by cancer, and develop educational resources to support the framework. The project method includes a wide consultation process, part of which was to hold a forum with people who have been affected by cancer.

Aim

The aim of the EdCaN Consumer Forum was to:

- 1) Seek the input from people who have been affected by cancer concerning the EdCaN project aims;
- 2) Gain the consumer's perspective on expectations of a Specialist Cancer Nurse;
- 3) Promote continuing engagement of people affected by cancer about the project and its outcomes.

Relevant Key Findings

Consumers attending the Forum identified a number of issues for nurses:

- There is a lack of nursing skills in some areas of cancer care i.e. in chemotherapy;
- General nurses need increased knowledge of cancer and there should be a minimum standard of information for nurses;
- Nurses should have access to professional development activities;
- Nurses should attend and proactively participate in multidisciplinary care teams, bringing a nursing perspective of the patient's needs to the team;
- There needs to be a recognition of nursing skills (not necessarily by money);
- Credentialling for specialist cancer nurses would be beneficial;
- Importance of mentoring within the nursing profession
- Nurses need improved multicultural skills and indigenous understanding.

Consumers also identified what they would have liked to experience:

- Validation of their feelings by nurses and the health care team;
- Consistent and standardised cancer care for all areas including rural and remote and linking of care from state to state;
- Access to social worker, counsellor and physiotherapist;
- Improved access to information for people affected by cancer and their families;
- Continuity of care from diagnosis to discharge;
- Follow up care and after hours access to information;
- Treatment summary to be provided to people affected by cancer;
- Person affected by cancer should be involved in decision-making about their treatment to the level that they desire;
- Benefits of positive contact with cancer survivors;
- Financial discussions with person affected by cancer and their families.

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In relation to the consumers' experience of Specialist Cancer Nurses, several consumers mentioned their positive experiences with Breast Cancer Nurses and the importance and benefits of this Specialist Cancer Nurse during their cancer journey. A number of other consumers believed they had been cared for by a Specialist Cancer Nurse, yet had only assumed that the nurse was a Specialist Cancer Nurse based on the area they worked in. Consumers considered that the care they had received from specialist cancer nurses differed from that of a general nurse.

Consumers commented on the draft competencies the project team had developed for the Specialist Cancer Nurse. Overall the consumers believed the competencies, comprising of four domains, were representative of the activities of a Specialist Cancer Nurse. The consumers provided constructive feedback on the wording of the competencies which will be used to inform future developments.

A discussion was held on developing information resources for people affected by cancer and what they should expect from a Specialist Cancer Nurse. The group believed that the information should provide knowledge to assist in making decisions, empower individuals and inform the multidisciplinary team. It should also be cancer type specific and explain their cancer journey.

Consumers also noted that they were interested in taking part in university curriculum to inform students of real cancer experiences.

Implications

The Forum allowed the EdCaN team to inform consumers of the project. It provided the opportunity to gain an understanding of the cancer experience from the perspective of people affected by cancer and how they view the role of a Specialist Cancer Nurse.

The involvement of consumers is crucial in the curriculum development and implementation phase of this project. Consumers provided a valuable insight into their personal experiences with cancer, which is an essential educational component for nurses.

Many consumers attending the Forum also expressed a willingness to advocate for the project, thus providing the opportunity to disseminate information to a wider audience. It was suggested that with such information, people affected by cancer may start to question their expectations for the type of nursing care received.

Finally the Forum has identified the willingness of people affected by cancer to continue working with the EdCaN project team which will be invaluable.

Consumer Groups who were represented at the Forum

We would like to thank the following organisations who facilitated representatives to come to the Forum: Cancer Voices Australia, Cancer Voices NSW, Cancer Voices Vic, Cancer Voices Qld, Cancer Voices SA, Cancer Voices ACT, National Breast Cancer Centre, Canteen, Leukaemia Association, Ovarian Cancer, Breast Cancer Action Group, Gynaecological Cancer Society, Breast Cancer Network Australia, Cancer Australia National Consumer Group, Colostomy Association