Patient engagement in cancer care
by Karyn Perry, RN, MBA, CON(C)

As healthcare continues to evolve, it is ever more important that patients be partners in care, not simply recipients of care as in older paradigms. Being a partner in care requires engagement in self-care, education and appropriate utilization of services, and has the potential to both reduce healthcare costs and improve health outcomes through the adoption of health-enhancing behaviours and the reduction of health inequities.1 Changing vocabulary reflects the evolving relationship between patient and care provider: compliance with care protocols gave way to adherence, to denote patient understanding and agreement with a chosen course of action. However, I believe it is time for a further evolution, to commitment, which more accurately reflects the patient’s engagement in their plan of care. This new relationship between healthcare provider and patient enables better decisions and improves the experience and satisfaction of patients, their carers and providers. While all healthcare professionals have a role in promoting patient autonomy and dignity across the cancer care continuum, nurses are especially well situated to foster patient and family engagement in cancer care.

The 2014 meeting of the Canadian Association of Nurses in Oncology (CANO/ACIO) focused on patient engagement. The transformation from patient as recipient of care to partner in care was described by Mr. Hugo Desrochers, a pilot with Air Canada at the time of his diagnosis with cancer. He recounted how his nurses authentically provided him information and detailed the impact of different choices. This enabled him to be fully engaged in his care, to make the best decisions for himself at each step along the journey, and helped his physical and emotional recovery. It also allowed him to assume an active role in his treatment. Referring to Reason’s Swiss cheese model of accidents (in which a number of minor mistakes or omissions line up to cause a major problem),2 he stated that being informed and involved in his care allowed him to shift the holes in the Swiss cheese and thus prevent adverse events.

The cancer care system is multilayered and stretches from prevention and screening to survivorship and end-of-life care. Oncology nurses are at the forefront at each stage and have a responsibility to question, identify and remove barriers to optimal care, be they inefficient and ineffective structures, or health inequities. Nurses are engaged in developing programs to facilitate seamless transitions of care, redesigning models of care, and advocating on behalf of patients to be sure their needs are met. The 2014 CANO/ACIO meeting highlighted work underway by oncology nurses across the country.

**REDUCING STRESS AT DIAGNOSIS**

During the initial frightening diagnostic phase, patients and families come face to face with system complexities and may find themselves ill-equipped to retain a sense of control during the process. Recognizing this phenomenon, numerous cancer centres are introducing diagnostic assessment programs (DAPs). At the Odette Cancer Centre in Toronto, nurses provide navigation, expert knowledge and psychosocial support aimed at enabling patients to become partners in their care, reducing distress and uncertainty, and increasing health literacy and improving access.3

**BARRIERS TO CARE**

There is increasing attention to social, political, economic and personal factors that impede access to health care, creating health inequities that become especially important in survivorship care. Nurses at the University of British Columbia are moving beyond simply describing these health inequities and are developing initiatives to engage patients in improving access to and quality of survivorship care.4 These mechanisms may be generalizable to other major transition points in the cancer care continuum, as demonstrated by nursing initiatives to work with patient advisory councils and include patients in quality improvement projects at the Jewish General Hospital in Montreal.5 These codesign methods incorporate the voice and expectations of patients, who work as partners in the design of high-quality care.

CANO/ACIO is committed to reflecting the movement toward patients as partners in care in the organization’s standards, guidelines and policy statements. A workshop was held aimed at renewing the Standards of Care (2001), which is the foundational document upon which all other CANO/ACIO documents are built.4 The changes will address fit and applicability of the Standards of Care to the current Canadian cancer care context, changing roles of nurses, shifting models of care, diverse care settings, patient engagement, and the changing needs of cancer survivors.

Next year, as CANO/ACIO celebrates its 30th anniversary, the conference will be held in Toronto, from October 4 to 7, embracing the theme, People, Purpose and Passion.

**References:**

5. Calestagne P, Bitzas V. Patients as partners: what our patients are telling us. 2014 CANO/ACIO annual conference; Quebec City.

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