Nurses Challenge the Status Quo in Cancer Care

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Introduction

Each year the Report Card seeks out innovations in cancer care. This year we spoke to advanced practice nurses or APNs whose focus is cancer. Advanced Practice Nurses are nurses with advanced degrees, usually masters and/or doctoral degrees who carry the title of Clinical Nurse Specialist or Nurse Practitioner. APNs across Canada were invited to share the innovations they have made to the cancer system and to cancer patient care. What they shared was astounding. This article provides the highlights of interviews with eight APNs from Alberta, Manitoba and Ontario.

ALBERTA

Krista Rawson

Krista Rawson is an NP and Senior Practice Consultant with Cancer Control Alberta (Cancer Plan 2030), who has created a sustainable workforce plan for NPs in cancer care. This feat is unique in cancer systems as little thought is given to the type of practitioner or role needed for excellent patient care and little planning has been done to enhance role implementation for nurses or introduction of new roles in what has traditionally thought to be physician territory. Krista developed a Community of Practice that meets monthly so that NPs in all parts of Alberta can discuss practice, ideas to advance patient care, role implementation, and workplace issues. Mentorship is active and continuous to promote knowledge about and respectful interaction with the health care team, patients and families. Context of the family is viewed as important in educating, dialoguing with and supporting patients and families to make appropriate decisions for their particular context and providing all aspects of supportive care wherever needed. In addition, Krista works with Universities and NP students to create a positive succession plan. Her work serves as a model for Canada.

Krista was charged with creating new models of care to meet specific patient needs across the province. Krista completed an environmental scan to determine what was working and what was not. She modified how roles were introduced and supported in the workplace. Since NPs in Alberta support communities to provide cancer care closer to home, models of care developed differ by region and available resources.

Support to patients and family members is an important part of the NP role.

Care and service innovations have expanded to include: rapid access clinics for lung cancer patients where these clinics provided first point of contact, assessment, treatment, navigation and education. Women with breast cancer on hormone treatment and patients in the curative treatment phase have access to an NP provider clinic offering one to one appointments as well as weekly group education. NPs offer support for sexual health issues where patients are seen by multidisciplinary team and are followed through treatment as needed. NPs follow patients with head and neck cancers and facilitate the transfer home with management of supplemental tube feedings as needed.

Support to patients and family members is an important part of the NP role in addition to assessments and management of treatment symptoms and complications. Similarly, NPs manage chemotherapy for GI patients and provide psychosocial support and education. NPs also follow patients with brain tumours and support the patient and family in advance planning and end-of-life decision-making.

Dr. Edith Pituskin

Dr. Edith Pituskin is an NP with a doctoral degree in Rehabilitation Sciences. She serves currently as a Clinician Scientist for Cross Cancer Centre in Edmonton. Edith has developed a rapid access cardiology clinic where patients have access to diagnostic imaging, dose timing, and surveillance of clinical outcomes. All patients seen in clinic become research partners by giving blood and tissue samples. From

these samples a data set is being built to determine and identify prognostic factors relative to treatment and clinical outcomes. Edith's vision is to identify through the samples and testing those patients at risk where increased surveillance is most useful. Although cardiac issues especially heart failure, have been problematic for patients and physicians for decades, this is the first research-based clinic to actively assess and address those issues. Edith invested in research and education and the result was that physicians now view this clinic as a valuable service and support it. Additionally, her research extends to patient experiences with radiation and caring activities of radiation oncologists and therapists giving radiation.

Edith is involved in the breast cancer clinic mentioned above, managing women on hormonal treatments. Drug adherence for this group is lower than desired for a good clinical outcome. The focus of education and support is around managing medications and using exercise and other means to maintain health, fitness and improve survival advantage.

MANITOBA

Dr. Anne Katz

Dr. Anne Katz is an advanced practice nurse working at CancerCare Manitoba. She is on the graduate faculty at University of Manitoba, Faculty of Nursing. Anne is a certified by the American Association of Sex Education Counselling and Treatment. Her practice is focused on providing information, education and counselling to people with cancer and their partners about sexual changes that can occur during and after treatment. Anne feels it is important for every cancer patient to be able to have a discussion about sexuality with their health care providers. Anne also educates and supports nurses and other health professionals to assess and discuss sexual changes and issues arising during treatment. In addition to face to face individual and couple counselling, Anne has written many books to help the public and health professionals understand the importance of sexual health and managing feelings in changing states such as during cancer treatment.

Anne receives referrals from medical and radiation oncologists, and nurses. Anne is located in the prostate cancer clinic but serves all cancer centre patients. She does brief resolution focused therapy identifying what is happening to the couple and the impact of the issue on their relationship. Anne validates the concerns the individuals have and in dialogue normalizes their concerns. She encourages open discussion with the couple to fully understand what each is thinking about the issues arising and the needs each has to move forward. Erectile dysfunction in prostate treatment interventions, colorectal and bone marrow transplant are common and may or may not be treatable. Information for couples is important and a likely outcome known in advance is somewhat easier to deal with going forward. Women with anal/rectal cancer may require dilation. This fact may increase or decrease emotions but recognition of the facts and how each one might help is useful. Anne recognizes the difficulty in dealing with sexual issue in the face of cancer and treatment but encourages commitment and flexibility as the couple works through the combined issues.

It is important for every cancer patient to be able to have a discussion about sexuality with their health care providers.

An example of Anne's work is found in the following vignette. A woman with breast cancer was treated with an aromatase inhibitor known to promote vaginal stenosis, vulvar atrophy both of which will cause pain with sexual touch. The woman was experiencing excruciating pain in sexual congress. Her partner was feeling guilty for hurting her and the woman felt guilty for not wanting to participate with her partner. Topical and locally applied estrogen was suggested and found to be helpful. Anne's advice for health care practitioners is "Just Ask!" It is important that patients have permission to talk and will look for cues from health care professionals to open a dialogue about treatment and psychological impacts on sexuality.

Kristie Morydz

Kristie Morydz, NP CancerCare Manitoba is part of a team who developed a smoking cessation program for patients, family members, staff members and their families as a primary cancer prevention modality. The idea was presented to ENT and surgical staff to lower risks for surgery and need for excess drug use. Rounds and team meetings were also used to identify issues and to implement this service. Evidence was gathered for a smoking intervention and guidelines for all staff were written, material for cancer patients was also developed on quitting smoking, effects of smoking on body and survival. Nursing students from University of Manitoba created the information booklet to support therapy. Treatment plans are being developed.

Kristie receives 5-6 new referrals each week (self-referral and HCP referral). Referees see the clinic nurse once per week to determine needs, issues and interventions. Pharmacists dispense the treatments and social workers counsel. Follow-up is intensive for 2-4 weeks. Kristie is part of the regional COP for Smoking Cessation and is able to bridge in and out patients without loss of follow-up or treatment. Distant patients are seen by telehealth and medications

are covered by Manitoba Health. Care can be readily coordinated and support sustained to maintain tobacco free lifestyle. Kristie has a primary role in the thoracic disease site group.

ONTARIO

Trillium Health Partners in Mississauga Ontario offered three dynamic advanced practice nurses.

Devi Ahuja

Devi Ahuja, NP Oncology in the Mississauga/Halton Central West Regional Cancer Program developed a survivorship program and well follow-up program. Women with breast cancer who have completed active treatment would normally be transferred back to the care of their GP. The well follow-up includes meeting supportive care needs until the patient feels ready to return to GP care. Quick re-entry is part of the well follow-up plan in the event of an issue or symptom needing scrutiny by oncology specialists. Quick re-entry decreases wait time from suspicion of an issue to testing and/or treatment. Cancer Care Ontario devised the concept and the Credit Valley site implemented it. A colorectal well follow-up clinic will begin soon developed with patient and GP input.

An outcome of this work is enhancement of transparency in communication with GPs and within the health care team onsite: developing care plans, summaries for the GP, toolkits for the GP around what to look for, how to manage patients and when to send them back to oncology. Feedback to date indicates enhanced satisfaction on the part of patients and GPs. Devi also created a lymphedema class with self-management information, physiotherapy assessments and treatment and attention to latent side effects, supportive care issues, diet, exercise and screening.

Charmaine Lynden

Charmaine Lynden, NP focusses on a range of disease sites in her practice in radiation oncology. She set up the processes to make the clinic run smoothly, for example she manages contacts and referrals from other Trillium sites, interacts with Emergency Departments, created processes for referrals, communication channels to GPs and other clinics. She manages lung cancer, esophageal/gastric/pancreatic cancer or anal/rectal cancer patients with concurrent radiation and chemotherapy at high risk for toxicity. Patients may come from any site of Trillium Health Partners so the need to organize and coordinate visits, tests and treatments is essential. She manages side effects and toxicities of radiation treatment. The GU group of patients will see her before surgery and continue to radiation therapy. Charmaine manages radiation patients admitted to hospital, directing their care plan for oncology crises such as spinal cord compression. She consults with palliative care and oncologists as needed.

Kathy Kiteley

Kathy Kiteley, CNS Palliative Care displays the broad scope of the Clinical Nurse Specialist role. She works with the Cancer Care Ontario initiative on the work of APNs in cancer care. She has a significant role in the Dyspnea Management Program developing evidence based guidelines, algorithms, patient information, DVDs that help patients through breathing, relaxation and guided imagery practices to reduce or manage dyspnea. She evaluated the program examining quality of life, and ESAS outcomes. She is seeking funding to sustain a Breathing Wellness Program developed from the earlier work. She is co-lead in the Registered Nurses Association of Ontario Best Practice Guideline on Pain Assessment and Management. She is part of a team looking at the knowledge translation of work done on symptom management. She has worked with other oncology nurses to develop a curriculum for end-of-life care for rural and urban nurses in Thailand. In her work setting Kathy provides palliative care to Trillium patients.

The most problematic issues for patients are fatigue and cognitive memory disruption.

Lynn Hryniuk

Lynn Hryniuk NP works in a private cancer navigation service which provides prevention, assessments, navigation and supportive care complementary to but not the same as that available in the cancer systems across Canada. Lynn is one of a number of Nurse Case Managers across Canada who assist patients to return to work after cancer and/or to rehabilitate to a new life status. Nurse Case Mangers walk patients through the diagnostic process, the diagnosis itself, cancer treatments, and educate on self-help strategies. They assist patients to positively manage side effects both long and short term. Referrals are made to the cancer centres, oncologists and GPs as the need arises.

The care is done by phone as often as the patient needs access to the nurse case manager. Nurses can be contacted for questions or concerns between planned phone contacts. Symptoms, issues and worries are discussed. The most problematic issues for patients are fatigue and cognitive memory disruption. Both influence their activities and successful return to work. Lynn encourages patients to monitor their activity level, need for naps and increasing or decreasing ability to be active. She discusses how to increase exercise tolerance and promotes the activities that patients enjoy. Lynn also examines the diet and promotes foods that increase energy and have a longer lasting effect on energy. Cognitive memory issues are frightening and frustrating and Lynn coaches patients to keep their minds active with reading,

crosswords and puzzles, but more importantly to maintain a sense of humour about forgetfulness when it happens. She counsels patients to do one thing at a time and finish it so that a sense of accomplishment is felt and an incentive to go on. Lynn works with the family physician or oncologist to consider issues with hemoglobin or thyroid when fatigue is prevalent. Specific plans for rehabilitation are made at a pace the patient can manage. Communication with regular health care providers is encouraged and patients are taught how to organize their thoughts, concerns and questions in preparation for these visits. NCCN Guidelines are used to manage care and symptoms arising so that care is the most up to date and evidence based. Medical personnel suggest drug treatments and suggest ways to find funding for these. Referrals are made with the patient's permission to resources and services for symptom management, but self -advocacy is encouraged.

The majority of work from diagnosis to end of life focusses on reclaiming and integrating a new life after cancer.

Back to work issues are raised and recommendations are made to employers for work modification and a guide for reintroducing a cancer survivor to the workplace. Supports for return to work issues in the psychosocial realm are also addressed such as concerns about what people at work will think. While patients may look good on return to work they very often experience fatigue with a new routine. Cognitive memory issues are often voiced as a concern. Plans are made with the patients for actions to be taken and when, for example if they can get through a day with activity at home they could likely mange a half day with the challenges of the workplace.

The majority of work from diagnosis to end of life focusses on reclaiming and integrating a new life after cancer. Lynn helps patients/survivors redefine their life status and manage work and relational issues. Survivors receive a Risk Assessment and focused education about how to further decrease their risk of cancer as well as heart disease, stroke, diabetes and osteoporosis. All survivors and their family doctors receive a Survivorship Care Plan and summary of what has happened in care. This plan indicates long term issues and symptom that may arise. Given the nature of late effects, Lynn is available for her cases to call and discuss issues as they arise for as long as is needed and well past graduation from the program.

End of life issues are raised as appropriate and plans are begun to address issues the patient wishes to resolve or address. Referrals are suggested or made on behalf of the patient to palliative care or pain and symptom management services.

CHALLENGES FOR APNS IN CANCER CARE

Palliative care, primary prevention and survivorship are not central to cancer control services. Still, these are recognized as important features of care by APNs.

Krista plans to create business cases and innovative partnerships around palliative care and survivorship to meet the needs of Albertans. Shared care models for long term metastatic disease are one possibility. Prevention in cancer centres is geared toward secondary prevention with assessments and treatment of late stage side effects. Krista is forward looking in the roles of NPs in cancer care. Strategies to decrease recurrence, weight management, exercise and other supports are being discussed as prevention measures to be integrated into care.

Edith is seeking funds to research the impact of exercise in hormonal treated women and those with metastatic breast disease. She is also seeking space for women to exercise and for an oncology rehabilitation centre that would create patient specific prescriptions for rehabilitation and exercise.

Anne is involved with a new field in Manitoba, onco-fertility and preservation issues for cancer patients. At present procedures and partnerships are being developed for sperm banking, cryopreservation of eggs and a fertility clinic.

Kristie is looking to develop smoking cessation plans with entire families of patients and staff to ensure greater support, positive role models and higher resolution to quit smoking.

Devi is considering the impact of opening new follow-up sites to accommodate the numbers of breast and colorectal patients and the possible need for after-hours clinic time in the Mississauga area. Two hundred patients have been referred to her since last fall. A new human resources structure developed by a nurse would be an exciting event.

Charmaine is examining the evidence for skin care products for patients with anal/rectal issues.

Kathy plans to make a difference in the emotional care of cancer patients by educating nurses in assessment of needs and interventions, how to start conversations and provide emotional care in a timed environment. She plans to study barriers and challenges for nurses, identify how to change viewpoints initiate self-reflection, identify what changes could be made and create a model for nurses to use in conversation and finally to create mentors to keep the movement going on behalf of cancer patients. Kathy is developing sustainable end of life care in a complex study of common practice, desired practices, and prognostic measures of death risk, advanced care planning and partnerships to provide and

maintain the best end of life care for cancer patients.

Lynn has worked in both public and private cancer care. Her hope is that patients get what they deserve, a unified consistent and cogent team that supports patients at all junctures of the cancer journey. The team she works with has published an evaluation of their service and patients agreed that the care they received was consistent, very helpful, timely and accessible and different from the care received in the cancer centre setting.

SUMMARY

APNs have made considerable changes in health care in general and cancer care in particular. Patients have confidence and trust in nurses but cancer agencies and hospitals are slow to utilize the expertise of nurses. The interviews with this group of cancer care providers demonstrated both the constraints they work under but also the drive to improve care for patients regardless of the limitations of cancer centre mandates. The 2014 Cancer System Quality Index released by the Cancer Quality Council of Ontario identified several hot issues in cancer care in Ontario with comparisons to other provinces. Wait times for surgical, medical and radiation treatments were found to be below the standard expected. Ongoing symptom assessment and management is lacking during and after the treatment phase. Survival rates are declining for women with breast cancer. Access to and use of palliative care was another issue raised. Given the expectation of rising cancer rates in the next two decades, it was surprising that no mention was made of human resource planning for cancer care. There is an obvious lack of skilled communication in the care setting about cancer issues, sexuality, end of life and symptom management assessments and interventions. All of these issues have been raised and addressed by the group of APNs.

The APNs interviewed were forward looking in their vision to change both services to patients and the cancer system itself. It behooves cancer administrators and government to access the vast expertise and support developments this group is already working on. The challenge of knowledge translation of these innovations is significant. Hopefully this Report Card will bring the depth of APN innovation to the attention of the public, administrators and government.

Dauna Crooks RN, DNSc recently retired from her position as Dean of Nursing, University of Manitoba and now resides in Dundas, ON. Dr. Crooks is Chair of the CACC.

THE FIRST STEP TOWARD AN ORGANIZED LUNG CANCER SCREENING PROGRAM[1]

Following new evidence that suggests screening via low-dose CT scans could help reduce lung cancer-related deaths in high-risk populations, the Canadian Partnership Against Cancer's pan-Canadian Lung Cancer Screening Initiative has developed the Lung Cancer Screening Framework for Canada to help interested provinces and territories design targeted early detection programs for high-risk populations.

It's estimated that 25,500 Canadians were diagnosed with lung cancer in 2013 and that some 20,200 men and women died from the disease in the same year. The five-year relative survival rate for lung cancer is 17 per cent.

The Framework eliminates duplication of efforts, saving time and resources that interested provinces and territories would otherwise have had to devote to developing their own approaches to lung cancer screening. It provides guidance to provinces that may be investigating the feasibility of lung cancer screening for high-risk populations and provides a framework of how to minimize the negative impact of opportunistic screening.

Lung cancer screening is focused on a defined high-risk population because the risks and complications associated with screening lower-risk cohorts, such as false positive findings, likely out-weigh any potential benefits.

Setting criteria for eligibility to participate in screening requires consideration of multiple factors, aside from risk exposure. Although conditions such as age eligibility should ideally be standardized across the country, as it is for colorectal cancer screening, lung cancer screening will likely evolve differently across the provinces and territories in terms of timing and approaches that best fit the needs of the jurisdiction.

The consensus statements within the Framework were developed through an extensive consultation process and involved clinicians, pathologists, radiologists, smoking cessation experts and thoracic surgeons, among others.

1. Canadian Partnership Against Cancer. Lung Cancer Screening Framework for Canada. 2015.