Editorial

Patient reported outcomes—A call to action

Over the past few months I have been hearing more discussion about patient reported outcomes (PROs) than ever before. It strikes me that this is an important topic for oncology nurses to pay attention to—and is an area where we could be leaders.

Patient reported outcomes are defined as any report coming directly from the patient about his or her health condition and its treatment (FDA, 2006). You may think that, as nurses, we gather information from patients all the time; so what is new? The difference about PROs is that the information from patients is gathered using standardized, validated measurement tools.

Measurement tools that have been standardized and validated have undergone what is called psychometric testing. This means their properties in terms of reliability, validity, sensitivity, and specificity have been evaluated. In essence, this testing gives us more confidence in the results from these tools and in drawing conclusions from the information they provide.

With standardized, validated tools we are in a better position to monitor patient status over time and compare results from one point in time to another. We have a common and consistent language to communicate with other members of the healthcare team. And, given the nature of the tools, everyone will have the same interpretation of the results.

In Canada, there is a good deal of work happening across the country to develop processes and systems for measuring and reporting PROs. This work is being called screening for distress in many cancer centres. The tools that are being used are the Edmonton System Assessment System (ESAS-r) and the Canadian Problem Checklist (CPC). The former captures patients’ perspectives about common symptoms while the latter captures more psychosocial issues or concerns. When an individual starts to come to a cancer centre, a first or baseline measure is taken using the tools; each visit thereafter, the patient completes the same tools. Over time, you can track what changes and what remains the same.

By having the patient complete the two instruments at each visit, you have a way of knowing what is of importance to that individual at that time and a way of comparing how things are proceeding from the patient’s point of view. And you can see over time if your interventions are actually working.

According to the CANO/ACIO Standards of Practice for Oncology Nursing, we have a key role in managing symptoms, teaching and coaching, and assisting patients and their families to cope with the consequences of cancer and its treatment. These responsibilities cannot be completed well without astute assessment using validated tools and focusing on what is of importance or concern to the individual patient. Routinely using PRO instruments in your assessment will give you a mechanism to triage patient concerns and set priorities for intervention during a busy clinical time. The results can set the stage for conversation with the patient and be a foundation for your care planning. PROs help you understand the impact of the disease and treatment, as well as the effectiveness of care on patients from the patient’s point of view. PROs can help you to identify patient concerns early so that you can mobilize action to combat any issues.

There is a prevailing notion within healthcare that, if you cannot measure it, you cannot improve it (Sir William Thomson). Having results from PROs will provide the opportunity to identify issues that need attention, monitor patient status over time, communicate with patients and with other members of the healthcare team, and identify gaps in care. Above all, it allows patient perspectives to be laid out and taken up, as the basis for care planning.

Embedding patient perspectives into care has been cited as a hallmark of quality in cancer care. Nurses can be leaders in this arena by incorporating the collection of PROs into their daily practice. With regular measurement and reporting of PROs, we can look beyond tumour-focused metrics (i.e., incidence and mortality, radiation fractions, chemotherapy doses) and better understand the patient experience with cancer care. We will also be in a better position to enact person-centred care.

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