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Do we have a clue: the treatment burden for the cancer patient

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Many who read *Cancer Nursing* have spent most of their professional career providing cancer patients with strategies to deal with their cancer treatments, and the symptoms and toxicities they generate. Those who conduct intervention research propose rigorous detailed intervention designs, to help cancer patients endure recommended therapies. Interventions are designed to assist patients to effectively manage symptoms and side effects or to assist them with coping with the emotional issues they may experience during treatment.

Our current research utilizes symptom management strategies to foster adherence with targeted oral oncolytic medications for patients with advanced disease.¹ As in previous research, the patients in this study have taught us that we do not have a clue! We had not considered the burden of taking oral oncolytics added to their lives. We had not come to appreciate how the addition of another intervention for advanced cancer patients, added more to their already complicated lives of living with cancer. Many of these patients are older, and most have additional comorbid conditions they are already managing. Most interventions for symptom management or adherence only assist patients with managing one chronic condition; but the more chronic conditions they have, the more work they need to perform, increasing their overall treatment burden. Here we discuss treatment burden for the patient with pre-existing chronic disease who now has a cancer diagnosis and propose recommendations for researchers to consider as they design interventions for clinicians to assist patients who are undergoing treatment with oral oncolytics.

Cancer patients today are living longer due to more effective cancer treatment. These same patients are surviving cancer while also living with and managing multiple other chronic conditions. Increasing multi-morbidity has brought increased care demands for patients with cancer and added considerations for health care providers. Patients with multiple chronic conditions, such as diabetes, hypertension, Parkinson's disease, who are diagnosed with breast, colon, or lung cancer, now have a quantum increase in the complexity and time they need to devote to their own ongoing care requirements. Depending upon how these conditions progress more time will be required to manage and coordinate their care. Current changes in cancer care, with shortened hospital stays and treatment with oral oncolytics, rather than IV chemotherapy, shift responsibilities and pose increased demands on cancer

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patients with other comorbidities. Patients not only need to manage symptoms and monitor to detect reportable side effects associated with all of their chronic conditions, but those on oral oncolytics also need to: obtain and administer their oral agents, implement dosing strategies (many of which have complex regimens, with variations in dosage with in one day, within cycles, and rest periods), observe for side effects, and separate out cancer-related side-effects from those that are associated with their other chronic conditions. Side effects associated with interactions between their cancer and other medications pose an additional problem for patients attempting to manage multiple chronic conditions. Thus, the daily work patients are expected to perform to manage their cancer is added to the work they are already doing for their comorbid conditions which must be integrated into their social, work and family roles. Frequently these treatment burdens occur among older patients with advanced cancer who also have little endurance, poor physical function, and multiple disease and treatment related symptoms.

Consider the following case:

A 68-year-old female newly-diagnosed with Renal Cell Carcinoma (RCC) in November 2014, now has progressed to stage IV with metastasis to the lungs and adrenal gland. She also has history of cardiovascular disease, hypertension, arthritis and renal failure. She is currently taking 17 medications, 13 of which were pre-existing before the initiation of the study. These included: multiple anti-hypertensives, diuretics, opioids, antiadrenergics, and supplements. Currently, the patient is being treated with the oral agent pazopanib at 800mg per day, to be taken on an empty stomach one hour before meals. However the patient was told to suspend this drug for 17-days due to hematuria and acute kidney injury (AKI). When this patient's medical record was audited for the five months she was on the trial we learned that she had undergone two surgeries and was hospitalized three times, for a total of 12 days. Also, she exhibited a number of the following symptoms: anemia, severe weight loss, dyspnea, febrile neutropenia, fatigue, and pain. This patient's health care setting was requiring her to be accountable and to explain changes in her health and to isolate which medication(s) are part of her problem. The patient needs to organize, and coordinate her own care and appointments, adhere to her medications and self-monitor two or three treatment regimens and carry out self-care of diet, exercise and other health behaviors, and daily life.

This real case exemplifies some of the challenges patients with a solid tumor cancer and multiple other chronic conditions need to manage. Consider the frequency of taking medications with different requirements as to when and how to schedule meals. This real case also exemplifies the challenges for the clinicians who work with the patient and the researcher who designs the intervention study and selects the outcome variable.

What does this mean for the clinician? Assessment tools need to be designed to evaluate the capacity of cancer patients with multiple chronic diseases and assist them to integrate recommended cancer care into their lives. Medication reconciliation, for example, will be a key consideration for this population. Clinicians also need to assess and assist with areas in which patients may need extra support and guidance. As we assist these patients we need to

consider challenges associated with health literacy, and the patient's physical and/or emotional capacity. We need to consider how to make their treatment burden less demanding, which will lead to better overall adherence to their medications. These issues need to be continuously assessed over the care trajectory, and adjustments made to usual planned and recommended care.

What does this mean for researchers? Intervention study designs need to consider multi-morbidity and treatment burden as study variables. We need to utilize measures to understand the extent that multi-morbidities affect the treatment burden in our studies. Counting the number of comorbidities does not capture the “load” of taking many medications. If one is planning an adherence study, how is adherence to the cancer drug to be assessed in light of the other drugs? If one has a symptom management intervention how are symptoms of CVD, hypertension, and arthritis separate from those of the cancer and cancer treatment. How do these factors affect the outcome variables? We need to think about how we sort out the etiology of symptom severity for symptoms that may also be associated with existing comorbidities, fatigue, pain, dyspnea, and limitations in function in patients with pre-existing comorbidities such as hypertension, congestive heart failure, and arthritis. The development of interventions that integrate the management or work of chronic disease into cancer management that makes the patient's work easier are needed to decrease patient load. We have to ask patients in our studies: do you think you can do what we are asking? How many hours per day are you already spending on care? How will you integrate this adherence and symptom management protocol? If we expect patients to follow our recommendations, we need to consider the work and time they are already spending and what we are asking of them. We need to consider how their existing care will influence implementation of our research intervention. Unless we determine what they already do, we will not know if it is something they can really do, and this will affect both the implementation of the study and the outcome.

We did not consider treatment burden in our current study, it is clear that we must! Without considering this, recruitment, retention and active engagement of participants in the intervention can be impacted. How does the treatment burden enter into patients' who refuse to participate and those who say I am overwhelmed or those who say I am not interested? We must understand treatment demands, what we are asking patients to do, and how this affects our research implementation and results.

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