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To Improve Cancer Treatment We Need to Have Patients and Care Teams Connected!

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We see on every street corner, every hallway, and every stop light, individuals using their smart phones. Yet, in healthcare we have been slow to adopt personalized communication with our patients. The research, however, shows that the connection a patient has with clinicians can improve health status outcomes through active participation which we often refer to as engagement when patients adhere to a medical regimen, report symptoms and carry out self-care.^{1,2} It is time that nurses and other clinicians consider how we can enhance communication connections with cancer patients so that we can identify toxic side effects, symptoms, poor levels of adherence, and introduce in more timely manners interventions that address areas such as symptom severity during active treatment.

Numerous intervention studies have documented how patients benefit from symptom management. Basch and colleagues³, Given and colleagues^{4,5}, Di Maio and colleagues⁶, and Sikorskii and colleagues⁷ have reported on the value of patient reported symptoms. Interventions responding to patient reported symptoms have shown improvement in symptom severity, symptom interference, and effects on physical function and emotional health. The impact of unmanaged symptoms on health system utilization is widely acknowledged. Common Terminology Criteria for Adverse Events (CTCAE) reports that the CTCAE may miss up to 50% of the side effects that cancer patients report.³

We have to wonder why better connection and communication with the thousands of patients who have unmanaged symptoms and side effects including pain is not an important identified research priority in reports such as the Cancer Moonshot Blue Ribbon Panel Report.⁸ Moreover, how much additional benefit might we be able to attribute to our treatments' effectiveness if we managed patient symptoms more effectively? Three decades ago we began investigating symptom status and management and today, as then, patients come to studies when in active treatment with an average of five to six unmanaged symptoms. Why have we made so little progress in the management of symptoms for which we have evidence?⁹

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Symptoms are disabling and can interfere with treatment, but often patients experience these alone in their own home, without clinician communication for self-care management. Early detection of symptom severity could alert the clinicians to changing patient conditions and results in early action to prevent medication interruptions or complications. This could prevent urgent care, emergency visits and hospitalization for unmanaged problems (ex. pain, vomiting, diarrhea, dehydration, and infection). There continues to be challenges and reservations in use of tele health and patient communication of symptoms. Patients often indicate that a history of the pattern of symptom experience between visits is not ascertained. Oncology providers see patient reported symptoms as less valuable and seem reluctant to make management decisions based on patient reported symptom data. If patient reports were valued by clinicians, they would be more directly assessed and monitored so that supportive decisions actions could be made. Clinicians still focus on laboratory tests drawn at weekly or biweekly intervals and see patients at their routine clinic visits and use this laboratory information to guide and adjust treatment. Two- way communication, being connected, to allow real time communication about unmanaged symptoms has to be considered if we are to improve the cancer experience for the patients.

Even though electronic medical record systems (EMR) are widely used, we have not seen rapid movement toward having patients add their symptom status to these EMR systems or even to report their symptoms using the number of symptom monitoring applications that exist. National Cancer Institute (NCI), American Society of Clinical Oncology (ASCO), and numerous pharmaceutical companies have free symptom reporting apps specific to cancer treatment. Some have the capacity to send the results on to the healthcare system. When queried about lack of use, healthcare professionals indicate that clinics are too busy to review symptom reports from patients, while others speak to the legal liability. This refusal to accept information from the patient is, we argue, a barrier to better patient connections and causes unnecessary patient suffering and may contribute to treatment alterations with subsequent effect on treatment outcomes. Overall this attenuates the quality of comprehensive cancer care that patients receive.

How are we going to integrate effective intervention into cancer treatment to actively and directly communicate and engage patients in their symptom management at home? Why given how we use smart phones for managing so many other parts of our lives are we unable to extend these lines of care between Cancer Centers and the patients they are treating?¹⁰

This will change overtime brought on by the demands of patients such as the millennials who will insist on being connected. Until that time, since nurses are responsible for much of the symptom monitoring and management, we can take the leadership to help set up systems and processes as standards of good care to help patients be connected during their active cancer treatment. If more research is needed to document the effectiveness, nurse researchers can do that research. Having patients connected to their professional team during active treatment moves toward care that would be truly more patient centered care - showing that we care about the patient's cancer experience.

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