From the Editor

Mining for information, participation in clinical trials

David H Henry, MD, FACP

As you read this month’s May issue of the Journal of Community and Supportive Oncology, the world will be making plans to attend the annual meeting of the American Society of Clinical Oncology (ASCO) in Chicago. Two things will happen there: investigators will present the latest, most important clinical and supportive care research findings in oncology, and leaders in the field will deliver educational session updates from the general to the most highly specialized areas of oncology. So how do we stay up to date in clinical practice these days? If you attend the major meetings of ASCO or the American Society of Hematology (ASH), then you will be fine assuming, of course, you brought your roller skates and reams of note paper to record all the sessions and are somehow able to distill it into a usable body of information for clinical practice when you get home. Of course, that is an impossible task for the approximately 80% of us who are hem-ons, let alone for the highly specialized 20% of us who practice in university settings. This got me thinking about 2 issues.

When was the last time you bought a text book and how often do you read your print journals? I would suggest that independent of attending the major meetings, there are 2 ways to get information to stay current with emerging trends in clinical supportive care and to keep your practice at the cutting edge. The first is to check for information on websites (such as the National Comprehensive Cancer Network site) for therapy guidelines or other state-of-the-art electronic sources of evidence-based advice or guidelines. The other is to routinely have information in the form of e-mail alerts (as in RSS feeds or even Twitter) or electronic newsletters arrive in your inbox from trusted sources such as ASCO, ASH, or major journals. These electronic alerts can cover all aspects of oncology practice and can be in the form of journal abstracts, articles, or electronic tables of content; news articles on clinical advances, practice trends, medical meetings, or health policy; and/or include podcasts or videos featuring our peers who are experts in their fields. The bottom line for making our selection of which of these to receive on a regular basis should be driven by the credibility of the source, the quality of the selected items and information, and whether the information is evidence-based and practice changing. Most major organizations and indexed journals have apps or electronic feeds that you can sign up for to get this information on a highly selective basis. Customization is key here, allowing you to refine your information feed based on your needs as a practicing a hem-onc or supportive care or midlevel provider and to deliver quality patient care.

But what about the clinical research that provides us with the substrate on which to base our practice of oncology? The findings reported at meetings are based on the slow, but steady clinical and basic research trials conducted by our colleagues worldwide. While our pediatric colleagues have somehow managed to keep clinical trial participation approaching 100%, the rest of us have an embarrassingly low rate of less than 5%. In this era of electronics and online medicine, why not take advantage of the web to improve clinical trial participation? I was struck by the findings in a study by Meropol and colleagues (J Clin Oncol. 2016;10:469–478) in which 1,255 patients were randomized to receive pre-oncology visit information sessions using either a text-based description of clinical trials or a web-based instrument intervention to address barriers to clinical trials. This pre- and post-intervention clinical trial found that both interventions yielded an increased understanding of clinical trials among the participants (all \( P < .001 \)), though the web-based intervention was superior to the text-based intervention (greater knowledge, \( P < .001 \); decrease in attitudinal barriers, \( P < .001 \)). Did the intervention help clinical trial participation? Yes – both interventions scored the same, with a 21% clinical trial participation in these patients who had been given pre-oncology visit information about their cancer and the utility of clinical trials. What an incredible improvement, and how graphically it illustrates the importance of informing and educating – and therefore empowering – our patients about their choices around treating and managing their disease.

This month’s issue of the Journal of Community and Supportive Oncology is very exciting. Included in the
line-up are Original Reports on the omission of dexamethasone from antiemetic therapy in breast cancer patients with hepatitis B or diabetes (p. 210), the prognostic significance of human papillomavirus status in post-op head and neck squamous-cell carcinoma (p. 215), and the role of caregivers among American Indian patients with cancer (p. 221). In keeping with our mission to ensure we deliver evidence-based content that can guide you in your daily practice, we feature a How We Do It article on survivorship care planning in a cancer center (p. 192) and a Review on the effects of exercise interventions during different treatments in breast cancer (p. 200). We also highlight the approval of trabectedin for sarcoma in our Community Translations section (p. 189), and revisit the management and treatment of multiple myeloma, based on the experiences of 2 practicing oncologists (p. 232). Finally, I wrote earlier about tracking down information that can help us in our daily practice of oncology. One source of information I did not mention was the Case Report, in which our fellow hem-oncs might report on a rare or unusual case they encounter in the course of their work and share the details of their diagnosis, treatment decisions, and the patient outcomes. This month, we feature a case on p. 229 about paraneoplastic syndrome and underlying breast cancer, in which a patient suffers with a worsening rash despite initiation of chemotherapy.
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Method: Data mining and data visualization techniques were applied to anonymized clinical trial data using both blinded and unblinded patient information. Patients with an elevated risk for specific adverse reactions were identified and risk categories were established to support future patient recruitment. Our objective was to identify the key factors pertaining to patient participation in clinical trials, to better understand the identified low participation rate of patients in one clinical research facility within Ireland. Design: Narrative literature review of studies focusing on factors which may act to facilitate or deter patient participation in clinical trials. Studies were identified from Medline, PubMed, Cochrane Library and CINAHL.