

ith increasing approvals of new immunotherapy agents and new indications for existing agents, more cancer patients are receiving immunotherapy in the community. Coordinated management of immune-related adverse events (irAEs) for these patients remains a growing challenge. For example, some patients may miss early opportunities to report symptoms of irAEs to their primary oncology team. Not only are early detection and management of irAEs vital for patient safety; if reported and managed early on, many irAEs are reversible.1 Thus, there is an urgent need to provide more effective patient education to ensure that patients and caregivers understand the importance of early, prompt communication about irAEs so that the primary oncology team can coordinate symptom management and improve clinical outcomes. Further, as more cancer patients receive combination regimens that include immunotherapy plus targeted agents, the issue becomes even more pressing, since irAEs may be more difficult to manage in this patient population.<sup>2</sup>

For its education project, "Real-World Experiences in Immunotherapy Delivery," ACCC had the opportunity to interview two cancer patients and an oncology nurse practitioner about common challenges in communicating about and managing irAEs. Their combined insights reveal how providers may communicate more effectively with cancer patients as they discuss the potential risks and appropriate management for irAEs. ACCC would like to thank these individuals for their time and willingness to provide valuable insights for this project:

- Ariella Chivil was diagnosed with Hodgkin lymphoma in 2010 and received immunotherapy in the setting of a clinical trial.<sup>3</sup>
- Mary Elizabeth Williams was diagnosed with stage IV melanoma in 2010 and received combination immunotherapy in the setting of a clinical trial.<sup>4</sup>
- Brianna Hoffner, MSN, NP, RN, is an oncology nurse practitioner at the University of Colorado Cancer Center.

#### **Explaining Immunotherapy**

Cancer patients may not understand how immunotherapy will treat their cancer. In addition, the topic of immunotherapy is often linked with many myths and misconceptions that have been driven by celebrities and the media. Therefore, before clinicians speak with patients about the risks of irAEs, it may be helpful to explain how immunotherapy works in the body. Open-ended questions like "Will you tell me about your understanding of cancer immunotherapy?" allow providers to meet patients where they are in terms of understanding how immunotherapy works and how it differs from traditional chemotherapy. For instance, an effective way to explain immunotherapy may be to discuss how the body fights an infection, such as a cold or a flu: The body recognizes the virus and attacks it with its own immune system. This example may help patients understand how cancer immunotherapy allows the body's immune system to recognize and destroy cancer. Patients who understand this may also better comprehend that while immunotherapy targets the tumor, it may also affect multiple organ systems in different ways and cause irAEs.

Patients report that they wish to receive information that is visual, easy to digest, and in a variety of formats that combine print and multimedia. For patients who have received prior chemotherapy, the discussion should cover how the side effects of immunotherapy are different from those experienced with chemotherapy and why irAEs are managed differently.

## **Practical Tips & Suggestions**

- Clinicians can use diagrams and pictures to illustrate how immunotherapy works in the body and how it may lead to irAEs.
- Patients who have received prior chemotherapy need to be reminded that while some irAEs may feel like the side effects associated with chemotherapy, irAEs are caused by different mechanisms and need to be managed differently.<sup>5</sup>

## **Understanding Patient-Centered Goals**

As oncology providers and nurses discuss potential irAEs with patients, the conversation should be a dialogue, not a lecture or presentation. Invite patients to engage as active participants of their care and openly express their concerns as treatment plans

are developed to reflect the patients' goals. By expressing empathy and understanding, clinicians can help foster a more trusting relationship with patients so that they feel safe and comfortable in discussing difficult topics such as bowel movements, menopausal symptoms, and reproductive fertility. They can also feel free to ask questions, openly express their concerns, and receive reassurance that their clinicians will aim to achieve the expressed goals of treatment. Clinicians who are compassionate, sensitive, and considerate in their comments and questions can help patients better absorb and process these emotionally heavy topics as they also think about the impact of their cancer diagnosis. Patients have expressed how their team members provided an atmosphere full of support where they "felt cared for" and where they gained tremendous encouragement as they received immunotherapy. Patients have also emphasized the importance of written notes and reminders, since they are prone to forgetting a significant amount of the information that was discussed at the provider's office.

## **Practical Tips and Suggestions**

- ✓ The discussion about irAEs should feel like a conversation, not a lecture or presentation.
- Patients with a cancer diagnosis are already in a highly emotional state; clinicians can make them feel more comfortable when discussing difficult topics such as bowel movements or reproductive fertility by expressing empathy and emotional understanding.

# Importance of Early Communication When irAEs Develop

As mentioned above, many cancer patients who receive immunotherapy may have also been previously treated with chemotherapy. Those patients may have experienced treatment-related toxicities and may recall how those adverse events were managed. If they experience similar symptoms while receiving immunotherapy, they may try to self-manage side effects that are potentially early signs of serious irAEs. As part of patient and caregiver education, clinicians can stress the importance of early communication when signs and symptoms develop, emphasizing that early intervention may significantly change the clinical course for certain irAEs.<sup>6</sup> When discussing irAEs with patients, express empathy and understanding about their potential reluctance to report symptoms because they do not wish to have their treatment discontinued. After validating their concerns about irAEs and about potential treatment discontinuation, engage in a shared decision-making conversation about their expressed goals of treatment and about safe and effective care that is supported by the best levels of evidence.

### **Practical Tips & Suggestions**

- Clinicians need to reinforce the importance of promptly reporting suspicious signs and symptoms that may be suggestive of irAEs.
- ✓ Patients can be reminded that they are not inconveniencing a member of the care team if they call at night or on the weekends to report signs and symptoms of a possible irAE.
- Patients can be empowered to trust in their team and to believe that the best clinical decisions will be made for them if they report an irAE.

While the cancer community continues to learn how to improve the diagnosis and management of irAEs, there is an increasing need to improve dialogue with patients and to effectively engage them as collaborative partners in their care. Clinicians can establish a safe atmosphere and trusting relationship so that patients can freely express their questions and concerns, knowing that their goals of treatment reflect their personal values and wishes. Clinicians can facilitate more open conversations with patients by knowing how to effectively use specific questions and phrases when explaining irAEs. They can also empathetically respond to verbal and emotional cues around sensitive topics. Patients can gain a realistic understanding of how immunotherapy will help their body attack their cancer and how irAEs need to be reported and managed.

#### References

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