Understanding immunotherapy terminology: An analysis of provider-patient conversations

Shannon Blee BS1 | Bari Rosenberg MD2 | Jeffrey M. Switchenko PhD3 | Rachel Hianik BS4 | Mary Catherine Thomson BS5 | Margie Dixon BS1 | Mehmet Asim Bilen MD1,6 | Rebecca D. Pentz PhD1,6

1 Winship Cancer Institute, Atlanta, Georgia, USA
2 Duke University Medical Center, Durham, North Carolina, USA
3 Rollins School of Public Health Emory University, Atlanta, Georgia, USA
4 UNC Chapel Hill School of Medicine, Chapel Hill, North Carolina, USA
5 Medical College of Georgia, Augusta, Georgia, USA
6 Emory University School of Medicine, Atlanta, Georgia, USA

Correspondence
Rebeca D. Pentz PhD, Winship Cancer Institute, 1365 Clifton Road NE, Atlanta, GA 30322, USA.
Email: rpentz@emory.edu

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Abstract

Background: Immunotherapy terminology is complex and can be difficult for patients to understand, threatening informed consent. The aims of this exploratory study are to determine whether patients understand immunotherapy terminology and if the provider defining the term improves patient understanding. Good patient/provider communication is important for good informed consent, patient adherence to treatment and patient outcomes.

Methods: Conversations between oncology providers and patients discussing immunotherapy were observed (n = 39), and technical terms used were noted. With consent, patients were interviewed post-conversation to assess their understanding of these terms (n = 39). Comparisons of the terms were conducted using chi-square tests, Fisher’s exact tests, or ANOVA where appropriate.

Results: “Immunotherapy” was the most difficult for participants to understand, with 48.7% (19/39) correctly defining immunotherapy. “Immunotherapy agents” was understood 53.8% (14/26) of the time. “Immune system” was well understood 88.5% (23/26). Providers defined immunotherapy in 97.4% of conversations. There was no correlation between having immunotherapy defined in the conversation, and the likelihood of a correct definition (p = 0.487). “Immune system” was defined in 92.3% of conversations (n = 26), and defining it in the conversation was correlated with increased patient understanding (p = 0.009).

Conclusion: Our results indicate that patients have difficulty understanding some immunotherapy terminology. Since patient understanding of key terminology is crucial for informed consent and patient care, it is essential to implement interventions to improve understanding.

Keywords
immunotherapy, immunotherapy terminology, informed consent, patient understanding, patient/provider communication

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1 | INTRODUCTION

The use of immunotherapy as a cancer treatment is rapidly expanding. Therefore, it is important that patients understand basic immunotherapy terminology. Misunderstanding of medical jargon can lead to lapses in communication, affecting treatment adherence, treatment initiation, and patient outcomes. Most important, in order to give informed consent for treatment, patients need to have a basic comprehension of terminology to ensure that they understand the potential risks and benefits of immunotherapy, its side effects, and what other options are available. Patients’ lack of understanding of basic immunotherapy terminology compromises true informed consent and their ability to make informed decisions about their treatment plan.

Patients’ misunderstanding of medical terminology is a well-documented issue across a multitude of specialties, including oncology. This is an issue that is not only prevalent in English-speaking countries, but the use of medical jargon has also been shown to negatively impact patient understanding in multiple countries. In Israel, one study found that providers use of medical terminology was the primary source of patient misunderstanding of discharge instructions in the Emergency Department. A study conducted in Africa determined that both the use of medical terminology and the difference in spoken language between patients and physicians contributed to patients’ lack of understanding. Previous studies examining contributing factors to patient’s lack of understanding have shown that providers sometimes struggle to communicate clearly with their patients, often misestimating their patients’ level of understanding. Many providers also find it difficult to translate complex medical terminology into lay language, jeopardizing good communication between the patient and the provider. Additionally, it is difficult for providers to know what and how much information to share. Although providers may believe that more information may lead to increased patient understanding, previous studies have shown that more information did not improve patient understanding or decrease anxiety about treatment and more information can actually lead to increased patient harm. Many patients also have limited health literacy and the complexity of certain treatments, such as immunotherapy, can pose a challenge for patients especially when providers are uncertain about how best to explain the therapy.

Given that immunotherapy is emerging as a more frequent treatment option, and that patient understanding is essential for informed consent and treatment adherence, the aims of this exploratory study were to determine whether patients understand basic immunotherapy terminology and whether the provider defining the term improves patient understanding. While there is extensive research about patient understanding of medical terminology in general, no research has been done to our knowledge about patient understanding of immunotherapy as explained by their provider. The goal of this report is to fill this gap and suggest several interventions to improve patient understanding of immunotherapy.

2 | METHODS

This study was approved by the Emory Institutional Review Board and all participants consented to participate. The study obtained data from three sources: (1) provider-patient conversations about PD-1 or PD-L1 checkpoint inhibitors; (2) post-conversation patient interviews; and (3) provider interviews.

Recruitment: Participants were recruited for participation in this study from outpatient oncology clinics at the Winship Cancer Center, Atlanta, GA, USA. Eligible providers were those who offered their patients treatment with a PD-1 or PD-L1 checkpoint inhibitor. Both patients on a clinical trial or receiving standard of care treatment were eligible. The sample was limited to conversations about checkpoint inhibitors in order to ensure homogeneity. Providers who consented to participate in the study were approached by a member of the research team at the beginning of clinic to inquire about potentially eligible patients, namely those with whom they would be discussing checkpoint inhibitors for the first time. The study was then discussed with eligible patients who signed consent prior to the start of their conversation with their provider.

The provider-patient conversation was observed and audio-recorded by the research assistant, who noted during the conversation when a provider used a technical term or listed a side effect. The post-conversation patient interview was modeled after a previous study and revised after a literature review. In order to assess patient understanding, the patient was asked to: Describe how immunotherapy works, describe the immune system, provide a definition for the additional technical terms used by the provider that were noted by the research assistant during the conversation, and list the mentioned side effects. Post-conversation interviews took place either in person immediately following the patient-provider conversation or over the phone within 1 week of the clinic encounter.

The provider interviews were conducted at the convenience of the providers. The questions posed to the providers included: What are barriers to effective communication about immunotherapy, what information they thought was important to communicate, and what educational tools could be useful to improve patient understanding of immunotherapy.

All data sources were audio-recorded, transcribed and qualitatively analyzed using the standard content analysis method and the qualitative data analysis software MAXqda (VERBI, GmbH, Berlin, Germany). Code books were created for each data source by two investigators, approved by the PI, and then all data sources (the patient/provider conversations, patient interview and provider interview) were double coded. Discrepancies (zero for provider-patient conversation; five for patient interviews, zero for provider interviews) were resolved by consensus. Frequencies of themes were tabulated. Correct understanding of the technical terms and side effects was first determined independently by the two coders, and then reviewed by an oncologist (MAB).

Descriptive statistics such as mean, median, standard deviation, and range were reported for continuous variables, and frequencies and
percentages were reported for categorical variables. Comparisons of the terms (correct vs. incorrect) were conducted using chi-square tests or Fisher’s exact tests, where appropriate, for categorical variables, and using ANOVA for continuous variables. As this is an exploratory study that was not hypothesis driven, we had a smaller sample size and therefore we did not attempt more complex models, such as multivariate models. Statistical significance was assessed at the 0.05 level, and the statistical analysis was conducted using SAS 9.4 (SAS Institute Inc., Cary, NC, USA). For terms mentioned more than 10 times (except for immunotherapy agents since multiple agents were discussed in one patient/provider interview, with some terms understood and other not understood), we assessed whether a physician defining a term correlated with improved understanding.

3 RESULTS

Forty-eight patients were approached about participation in this study and 39 (81%) patients consented to participate. Three of the patients approached were ineligible either due to cognitive impairment resulting in an inability to understand the researcher’s explanations, or because immunotherapy was not being discussed during their visit. Five participants refused due to time constraints or feeling unwell. One patient was excluded since he was not from sites included in the approved protocol. Participants were patients from melanoma, breast, lung, gastrointestinal, and genitourinary cancer clinics. The median age of the 39 interviewed patients was 58 years (range: 25–79, SD: 12.67); 22 were male (56.4%); 31 were Caucasian/white (79.5%), and 21 had some college education or more (55.3%). The demographics of all patient participants are shown in Table 1.

Twenty-five oncology providers were interviewed (17 physicians, four Doctors of Pharmacy, two physician’s assistants, and two nurse practitioners). The providers were from differing specialties including: genitourinary (GU), melanoma, aerodigestive, breast, gastrointestinal (GI), and lung (Table 2).

Eighteen different technical terms were used throughout the 39 transcribed conversations. In tallying the number of terms, we grouped the four names of the different PD1 and PD-L1 inhibitors (Pembrolizumab, Ipilimumab, PD-1, Nivolumab) into one term entitled “immunotherapy agents.” The frequencies of being defined by the provider and of being correctly defined by the patient were determined for nine of the terms (Table 3). The other nine technical terms were only mentioned once in the conversations, making them too infrequently mentioned to be analyzed. These terms included: high mutation burden, higher risk profile, randomization, colitis, false progression, toxicity, cytokine, systemic therapy, and central catheter. For 17/18 of the technical terms used, the provider usually provided a definition (75%–100% of the time). Of the six times mentioned, “maintenance” was the only technical term more frequently undefined (n = 5; 83.3%) than defined (n = 1; 16.7%). The two most frequently used technical terms in conversations were “immunotherapy” and “immune system.” Immunotherapy was used in all 39 conversations. Providers defined “immunotherapy” in 97.4% (28/29) of conversations. “Immune system” was used in 26 conversations and defined in 24/26 (92.3%).

In the post-conversation interview, the term “immunotherapy” was the most difficult term for participants to understand with less than half (19/39; 48.7%) correctly defining immunotherapy. “Autoimmune” was also a difficult term for patients to understand, with

### Table 1: Patient participant demographics

| Characteristics | N = 39 | % |
|-----------------|-------|---|
| Disease site    |       |   |
| Melanoma        | 22    | 56.41 |
| GU              | 7     | 17.95 |
| Breast          | 3     | 7.69 |
| GI              | 6     | 15.38 |
| Lung            | 1     | 2.56 |
| Gender          |       |   |
| Male            | 22    | 56.41 |
| Female          | 17    | 43.59 |
| Age             |       |   |
| 25–39           | 4     | 10.26 |
| 40–49           | 11    | 28.21 |
| 50–59           | 7     | 17.95 |
| 60–79           | 17    | 43.59 |
| Ethnicity       |       |   |
| White/Caucasian | 31    | 79.49 |
| Black or African American | 6 | 15.38 |
| Other           | 2     | 5.13 |
| Educational level |       |   |
| Less than high school | 3 | 7.69 |
| High school     | 14    | 35.9 |
| College graduate| 13    | 33.3 |
| Graduate school | 8     | 20.51 |
| Refused         | 1     | 2.56 |
| Income²         |       |   |
| Less than $50,000 | 15  | 38.46 |
| $50,000–99,999  | 14    | 35.9 |
| $100,000–$149,999 | 4  | 10.26 |
| $150,000 or greater | 0  |   |
| Refused         | 6     | 15.38 |

³Last grade or year that the participant completed school.
²Participant’s personal annual income before taxes.

### Table 2: Provider participant specialties

| Specialty       | N (%) |
|-----------------|-------|
| Aerodigestive   | 4(16) |
| GI              | 4(16) |
| PharmD          | 4(16) |
| GU              | 3(12) |
| Melanoma        | 2(8)  |
| Breast          | 2(8)  |
| Lung            | 2(8)  |
| NP              | 2(8)  |
| PA              | 2(8)  |
4 participants (4/9; 44.4%) correctly defining it in the 9 conversations in which it was mentioned, even though providers defined it 88.9% (8/9) of the time. "Immunotherapy agents" was understood 53.8% (14/26) of the times mentioned and interestingly "immune system" was well understood (23/26; 88.5%). There was no association between having "immunotherapy" defined in the conversation, and the likelihood of a correct definition (Defined 47% (18/38 correct) vs. Not defined 100% (1/1), p = 0.487); however, defining "immune system" in the conversation was associated with increased patient understanding (Defined 96% (23/24) vs. Not defined 0% (0/2), p = 0.009). The only demographic characteristic that was significantly associated with understanding "immunotherapy" was having a family member with cancer (p = 0.031).

Participants’ correct identification of the side effects of the proposed immunotherapy and their frequency are reported in Table 4. Five of 39 (13%) participants could not identify any side effects. Of the correctly identified side effects participants most often correctly identified "colon issues/diarrhea" (19/72; 26.39%) and of the incorrectly identified side effects, participants most often incorrectly listed nausea, vomiting, or stomach problems (11/23; 45.83%).

Providers reported ten types of information they felt were important to communicate to patients including: the side effects of immunotherapy (24/25, 96%), a realistic view of the benefit of immunotherapy (16/25; 64%), the mechanisms of action of the treatment (9/25; 36%), the logistics of treatment (9/25; 36%), the fact that immunotherapy is not always available as standard of care treatment (2/25; 8%), the concept of pseudo progression (2/25; 8%), how immunotherapy differs from chemotherapy (2/25; 8%), indications for use of immunotherapy (2/25; 8%), and alternative options (1/25; 4%). They also identified eight barriers to communicating with patients about immunotherapy shown in Table 5.

To find solutions to the noted barriers, providers were asked about the potential helpfulness of eight different educational tools in explaining immunotherapy to patients. One provider did not answer any questions about solutions and therefore was excluded in the count. Pamphlets or other written information for patients explaining key facts about immunotherapy were identified as potentially helpful by 91.67% (22/24) of providers. Other educational tools included a website explaining key facts (13/24; 54.17%), a patient video (9/24; 37.5%), scripts for providers to use for immunotherapy conversations (2/24; 8.33%), and feedback from this study, interacting with past patients, an interactive PowerPoint presentation, and information from multiple providers, each deemed helpful by 4.17% (1/24) of providers.

### Table 3

Nine analyzed technical terms with the four immunotherapy treatments combined into one technical term ("immunotherapy agents")

| Term (n = # of times mentioned) | Defined (% of mentioned) | Understood (% of mentioned) |
|---------------------------------|--------------------------|----------------------------|
|                                 | Yes  | No  | Not mentioned | Yes  | No  |
| Immunotherapy (n = 39)          | 38 (91.4) | 1 (2.6) | 0 | 19 (48.7) | 20 (51.3) |
| Immune system (n = 26)          | 24 (92.3) | 2 (7.7) | 13 | 23 (88.5) | 3 (11.5) |
| Immunotherapy agents (n = 26)   | 26 (100) | 0 | 13 | 14 (53.8) | 12 (46.1) |
| Autoimmune (n = 9)              | 8 (88.9) | 1 (11.1) | 30 | 4 (44.4) | 5 (55.6) |
| Maintenance (n = 6)             | 1 (16.7) | 5 (83.3) | 33 | 2 (33.3) | 4 (66.7) |
| Combination treatment (n = 5)   | 5 (100) | 0 | 34 | 5 (100) | 0 |
| White blood cells (n = 4)       | 4 (100) | 0 | 35 | 3 (75) | 1 (25) |
| Adjuvant treatment (n = 4)      | 3 (75) | 1 (25) | 35 | 1 (25) | 3 (75) |
| Microsatellite stability (n = 3)| 3 (100) | 0 | 36 | 0 | 3 (100) |

### Table 4

Percentage of patients that had correct and incorrect identification of side effects of the proposed checkpoint inhibitor in the post-conversation interview

| Side effect | Correct identification N = 72 (%) | Incorrect identification N = 23 (%) |
|-------------|-----------------------------------|------------------------------------|
| Colon issues/diarrhea | 19 (26.39) | 1 (4.17) |
| Nausea/vomiting/stomach problems | – | 11 (45.83) |
| Skin issues | 11 (15.28) | 1 (4.17) |
| Hormone problems | 10 (13.89) | – |
| Lung issues | 8 (11.11) | – |
| Liver problems | 6 (8.33) | – |
| Flu-like symptoms | 5 (6.94) | 2 (8.33) |
| Heart problems | 5 (6.94) | – |
| Pancreas issues | – | 1 (4.17) |
| Kidney problems | 4 (5.56) | – |
| Fatigue | 1 (1.39) | 2 (8.33) |
| Depression | 1 (1.39) | – |
| Diabetes | 1 (1.39) | – |
| Arthritis | 1 (1.39) | – |
| Autoimmune conditions (Lupus, Crohns disease) | – | 3 (12.5) |
| Blood counts drop | – | 1 (4.17) |
| Neuropathy | – | 1 (4.17) |
| Hair loss | – | 1 (4.17) |
TABLE 5 Provider-identified barriers to communicating with patients about immunotherapy

| Barrier                                        | N = 25 (%) |
|-----------------------------------------------|------------|
| Misconceptions about immunotherapy’s benefit | 12 (48)    |
| Misinformation from other sources: web, friends | 8 (32)    |
| Misconceptions about immunotherapy’s risk (i.e., Confuse with chemotherapy) | 6 (24) |
| Complexity of immune system/ organ system    | 4 (16)     |
| Differing levels of medical literacy         | 3 (12)     |
| Time/ clinic space logistics                 | 2 (8)      |
| Identified no barriers                       | 2 (8)      |
| Explaining pseudo progression                | 1 (4)      |
| Only want to hear about immunotherapy and no other options | 1 (4) |

4 | DISCUSSION

For proper informed consent, patients need to have a basic understanding of the technical terms used by their provider and a general knowledge of the proposed treatment. The results from this exploratory study show that patients may not understand some of the technical terms used by their providers in initial discussions about immunotherapy. Although providers defined the term “immunotherapy” in the majority of conversations, most patients (51%) still had difficulty providing a correct definition of the term in the post-conversation interview. Similarly, the four immunotherapy agents were defined in all the conversations in which they were mentioned but understood in a little over half (53.8%). "Immune system" was better understood (89%) and a provider definition was correlated with participants correctly defining the term. These differences in participant understanding may simply be due to "immune system" being a lay term, while "immunotherapy" and the particular immunotherapy agents mentioned, are new terms and therefore are not as readily understandable. Additionally, since immunotherapy is a more complex treatment, it may be more difficult for providers to translate it into readily understandable language, which is why a provider definition does not work to increase understanding. Not surprisingly, previous experience with cancer treatment, rather than a definition, helped improve understanding; participants who had a family member with cancer were more likely to correctly define immunotherapy than participants who did not. Our results are congruent with past studies that showed patients struggle to understand medical terminology.

As the providers noted in the post-conversation interview, there are many barriers that pose challenges to effectively communicating with patients about immunotherapy, with the most common being misconceptions about its benefits and misinformation about its use. As proper communication impacts not only informed consent, but treatment adherence, treatment initiation, and patient outcomes, it is imperative to improve provider-patient communication. We suggest two methods of improving communication (Figure 1). First, our past studies have provided evidence that provider use of metaphors may work to enhance patient understanding of terminology. Hianik et al., showed that more than half of participants understood metaphors used for describing how immunotherapy works. These findings offer a way to improve patient understanding during a conversation with their provider.

Second, the study team is in the process of developing short, animated videos explaining the immune system, immunotherapy, and immune cells, a technique shown to be equally successful in improving understanding of terms about chemotherapy. The chemotherapy videos proved to be successful in both urban and rural populations, indicating that they appropriate and effective across varying demographic groups. Although these immunotherapy videos have not yet been tested, we believe that the immunotherapy videos could be equally as successful at improving patients’ understanding of these complex concepts given that video-based interventions have been proven effective in a multitude of settings. Our future plans include testing the videos. Of note, the majority of providers interviewed felt strongly that it is important for patients to understand the side effects of immunotherapy and the realistic benefit of immunotherapy, and welcomed a variety of interventions including pamphlets, information on websites and videos.

There were a few notable limitations to this study. All patients were recruited from outpatient clinics in the same cancer center, limiting its generalizability. Only conversations about PD-1/PD-L1 immune checkpoint inhibitors were used for this study, though immunotherapy broadly encompasses many other types of therapies. Additionally, since some of the terms were not frequently used, we could not perform a statistical analysis to determine if certain demographics were correlated with understanding. Although, the providers did mention side effects in the conversations, no conclusions can be reached about them since later conversations with the pharmacists typically go into more detail about side effects. There was a hint, however, that patients are confusing immunotherapy with chemotherapy—one fourth of the providers mentioned this as a barrier to understanding—since the most frequently misidentified side effect (nausea/vomiting) is a common side effect of chemotherapy. Finally, given the small sample size for this study, we did not attempt more complex statistical analyses. As this was an exploratory study of patient understanding of immunotherapy, further studies are needed to determine the generalizability of the results.

5 | CONCLUSION

Interviews with patients after a conversation with their provider about immunotherapy show that patients have difficulty understanding some immunotherapy terminology. Since immunotherapy is a relatively new therapy, but rapidly growing as a treatment option for a variety of cancers, it may be more difficult for providers to translate it into lay language. The novelty of immunotherapy and its mechanism of treatment could be why patients lack understanding, even when provided with a
definition. Since patient understanding of key terminology is essential for adequate informed consent, it is essential to implement validated interventions to improve understanding.

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CONFLICT OF INTEREST
Dr. Bilen has acted as a paid consultant for and/or as a member of the advisory boards of Exelixis, Bayer, BMS, Eisai, Pfizer, AstraZeneca, Janssen, Genentech/Roche, Seattle Genetics, Incyte, Nektar, AstraZeneca, Tricon Pharmaceuticals, Peleton Therapeutics, and Pfizer for work performed not associated with the current study.

ORCID
Shannon Blee BS  https://orcid.org/0000-0002-9110-8281

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SUPPORTING INFORMATION
Additional supporting information may be found in the online version of the article at the publisher’s website.

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