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Research Article

The Experiences of Cancer Patients Receiving Immunotherapy: A Qualitative Study

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Objective: The use of immune checkpoint inhibitors in cancer treatment provides significant clinical benefits, but it is also associated with some side effects. While these drugs enable the immune system to respond more aggressively to cancer cells, they can sometimes lead to excessive immune responses that may damage normal tissues. This qualitative study aims to explore the experiences of cancer patients receiving immunotherapy.
Methods: This study is a qualitative research conducted on the experiences of cancer patients receiving immunotherapy at a university hospital in Istanbul, Turkey, between June 2024 and January 2025. The standards for reporting qualitative research studies reporting guidelines were used to report this study. Data collection was conducted through semistructured face-to-face interviews.
Results: This study explores the experiences of cancer patients undergoing immune checkpoint inhibitor treatment. The research identified five main themes. These themes include patients' anxiety and uncertainty about the disease process, their need for information, feelings of trust, expectations for the future and hope, economic problems, and financial burdens, as well as gaps in knowledge regarding treatment-related toxic effects.
Conclusion: This research has provided valuable insights into the experiences and challenges faced by cancer patients receiving immune checkpoint inhibitor treatment. It highlights the need for healthcare professionals to inform patients about the treatment process and potential side effects and to properly manage their expectations regarding the effectiveness of the treatment.

Keywords: cancer; immune checkpoint inhibitors; immunotherapy; qualitative research; supportive care

1. Introduction

Immune checkpoint inhibitors (ICIs) have introduced a revolutionary approach to cancer treatment and have led to successful outcomes in the treatment of many types of cancer in recent years. ICIs work by enhancing the immune system's ability to respond more effectively to cancer cells, creating a new treatment strategy aimed at preventing cancer progression. This treatment method, particularly by targeting the checkpoints that prevent the immune system from recognizing and destroying cancer cells, improves the quality of life for cancer patients and enhances treatment outcomes. ICIs are generally better tolerated than chemotherapy, cause less systemic toxicity, and allow shorter or less frequent treatment regimens in some patients. These factors improve patients' quality of life, both in terms of reduced physical side effects and a more psychosocially sustainable treatment process [1, 2]. The clinical successes of ICIs are increasingly solidifying their role in cancer therapy and securing approval for use in many cancer types [3–5].

The use of ICIs in cancer treatment provides significant clinical benefits, but it is also associated with some side effects. While these drugs enable the immune system to respond more aggressively to cancer cells, they can sometimes lead to excessive immune responses that may damage normal tissues. This can result in immune-mediated

inflammatory side effects. Common side effects include skin rashes, fatigue, diarrhea, elevated liver enzymes, and organ toxicities caused by the immune system targeting healthy organs. A classification-based meta-analysis of immune-related adverse events (irAEs) according to organ systems has identified a range of effects: dermatological reactions such as pruritus, rash, maculopapular eruptions, vitiligo, and dermatitis; endocrine disorders including hypo/hyperthyroidism, hypophysitis, thyroiditis, and adrenal insufficiency; gastrointestinal issues such as colitis, diarrhea, pancreatitis, and elevated liver enzymes (AST and ALT) or bilirubin; respiratory complications including pneumonitis, pulmonary infiltrates, and interstitial lung disease; and renal events such as increased creatinine levels, nephritis, and renal failure. In patients receiving PD-1 pathway inhibitors, the pooled incidence of irAEs of any grade was approximately 26.8% (95% CI: 21.73–32.61; $I^2 = 92.8$), while the incidence of high-grade events was around 6.1% (95% CI: 4.85–7.64; $I^2 = 52.0$) [6]. Although rare, these drugs can trigger autoimmune diseases or worsen pre-existing autoimmune conditions. Side effects should be monitored throughout the treatment period, and adjustments to the treatment should be made as necessary. However, the side effects of ICIs can generally be managed by pausing treatment or with appropriate immunosuppressive therapies [7, 8].

While quantitative studies have provided valuable data on the clinical outcomes and adverse event profiles of immunotherapy, they often do not capture the lived experiences and subjective perceptions of patients undergoing such treatments. This qualitative study aims to address this gap by exploring the experiences of cancer patients receiving immunotherapy. Through in-depth exploration of patients' perspectives, this approach allows for a richer understanding of how individuals make sense of their treatment, cope with side effects, and integrate immunotherapy into their daily lives. Gaining such insights is critical for informing patient-centered care strategies and improving the overall quality of the treatment experience. A review of the literature reveals that qualitative studies on the experiences of patients during the immunotherapy process are quite limited. This gap could pose a serious problem, particularly in situations where patients experiencing immune-related side effects may be unaware that they should seek oncology care rather than acute medical assistance or emergency services. Therefore, more comprehensive research and planning are needed to provide patient-centered, high-quality, safe, and effective care during and after cancer immunotherapy treatment. These gaps constitute a barrier to the effective management of treatment processes. For this reason, this qualitative study aims to explore the experiences of cancer patients receiving immunotherapy.

2. Materials and Methods

2.1. Study Design. This study is a qualitative research conducted on the experiences of cancer patients receiving immunotherapy at a university hospital in Istanbul, Turkey, between June 2024 and January 2025. The standards for reporting qualitative research studies (SRQR) reporting guidelines were used to report this study.

2.2. Sample. The inclusion criteria for the study were as follows: patients aged 18 and over, willing to participate, without communication barriers, diagnosed with cancer, receiving only ICI treatment (at least two cycles), informed about their disease status, and without communication difficulties. Patients with mental or cognitive disorders, those who were unable to participate in the Turkish interview, and those who did not volunteer to participate in the study were not included in the study. The researchers selected potential participants through medical oncologists or nurses, and patients who were interested in participating were provided with detailed information about the purpose of the study by the research team. In this study, patients did not receive any formal or structured education. The treatment decision and basic information about the ICI therapy, including its purpose and potential side effects, were provided verbally by the treating physician as part of routine clinical care prior to the initiation of ICI therapy. The study was approved by the Istanbul Aydin University Ethics Committee (2023/04), and informed consent was obtained from all participants. The research sample was determined using purposive sampling and analyzed in accordance with the qualitative research design. Data collection was completed when no new information emerged and the sample size reached saturation. The study was completed with a total of 12 patients.

2.3. Data Collection. Data collection was conducted through semistructured face-to-face interviews. Prior to the interviews, a literature review was conducted, and based on this review, a preliminary interview form was created. After conducting three pilot interviews, an interview guide containing the topics shown in Table 1 was prepared. The time and place for the interview with each patient were mutually agreed upon by the interviewer (Dilek Yildirim), ensuring that the environment was quiet and uninterrupted. During the interviews, the interviewer used a voice recorder to record the conversations, while carefully noting the participants' facial expressions, body movements, emotional responses, and other nonverbal behaviors. The interviews lasted between 30 and 45 min.

2.4. Data Analysis. The interview data were recorded after personal information was removed and transcribed into full text. The transcripts were carefully reviewed by two independent researchers (Dilek Yildirim and Ferda Akyuz Özdemir). In data analysis, an interpretive description approach was used. This approach allows for explanations that add meaning to the research findings, going beyond simple description. Interpretive description, particularly in health and practice-based disciplines, provides clues on how the findings can be applied in practice. The data analysis process was inductive. The researcher proceeded without bias to explore the data and relationships within them. This approach aims to derive general conclusions from individual cases. After reading and reviewing the transcripts, initial categories were identified using open coding, and these categories were then divided into subthemes. Subthemes

Table 1: Interview guide questions.

Number	Interview guide questions
1	Could you share your experiences regarding the disease and treatment?
2	What were your thoughts when your doctor recommended immunotherapy?
3	When making a decision about immunotherapy, what kind of information would you have liked to receive from your treatment team?
4	How do you think immunotherapy works in treating your condition?
5	What do you know about immunotherapy?
6	Are there any other aspects of immunotherapy you would like to be informed about?
7	What kind of discomforts did you experience during immunotherapy, and how did they affect your life?
8	How did you cope with these uncomfortable experiences?
9	Overall, what were the positive and negative effects of immunotherapy on you?
10	Did you face any challenges or concerns during the immunotherapy process?
11	What treatments did you undergo before starting immunotherapy, and what were the results?
12	In your opinion, what are the similarities and differences between immunotherapy and other treatments you have received?
13	Is there anything else you would like to note or add?

were merged into broader themes based on similarities and connections. Discussions were held among the research team until consensus was reached on the results, and a final evaluation of the findings was made. Dilek Yildirim and Ferda Akyuz Özdemir selected appropriate quotes to highlight repetitions between themes.

2.5. Ethical Considerations. In order to conduct the study, the research team provided detailed information to the patients regarding the purpose of the study. The study was approved by the Istanbul Aydin University University Ethics Committee (2023/04), and informed voluntary consent was obtained from all participants. The study was carried out in conformity with the principles of the Declaration of Helsinki.

3. Results

Between June 2024 and January 2025, 28 eligible patients were identified, and 12 patients consented to participate. 16 patients declined participation, citing a lack of time or unwillingness to be interviewed. In total, interviews were conducted with 12 individuals. The patients were asked the questions listed in Table 1.

The average age of the patients was 58.33 ± 16.19 years, and the average duration since diagnosis was 2.17 ± 1.34 years. When examining the gender distribution of the patients, it was found that 41.7% were female ($n = 5$) and 58.3% were male ($n = 7$). Regarding the marital status, 58.3% were married ($n = 7$), and 41.7% were single ($n = 5$). When looking at the education level, 33.3% were literate ($n = 4$), 33.3% were elementary school graduates ($n = 4$), 25.0% were high school graduates ($n = 3$), and 8.3% had a university degree or higher ($n = 1$). The majority of participants, 58.4%, were retired ($n = 7$). In terms of income, 66.7% of patients had a middle-income level ($n = 8$), and 50.0% had quit smoking ($n = 6$). Regarding alcohol consumption, 58.3% of the patients were found to consume alcohol. In terms of tumor types, 58.3% of participants had lung cancer ($n = 7$), 8.3% had breast cancer ($n = 1$), 16.7% had prostate cancer ($n = 2$), and 16.7% had ovarian cancer ($n = 2$). When evaluating the disease stages, 58.3% were in stage III ($n = 7$), and 41.7% were in stage IV ($n = 5$). Regarding the use of ICIs, 58.3% were using Nivolumab ($n = 7$), 8.3% were using Ipilimumab ($n = 1$), and 33.3% were using Atezolizumab ($n = 4$) (Table 2).

3.1. Anxiety and Uncertainty Related to the Disease Process. Participants emphasized the emotional challenges they faced after being diagnosed with cancer and the uncertainties related to the treatment process. A lack of information regarding the severity of the disease and treatment options created anxiety and concern. The statements of four different patients are as follows:

> *"At first, I was scared. It's a new drug, but it seemed like a drug with uncertain results. I talked to my doctor, and after explaining, I trusted it."*

> *"At first, I was worried because it was a new treatment method. But my doctor explained how it strengthens my immune system to fight cancer cells, and that changed my approach to the treatment."*

> *"I started immunotherapy, but I don't know how long my response will last or if it will be permanent. Living with this uncertainty is hard."*

3.2. The Need for Information. Patients expressed a desire to receive more information about the mechanism of immunotherapy, success rates, potential side effects, treatment duration, and support resources. This lack of information made it difficult for them to make treatment decisions. Additionally, patients mentioned that immunotherapy aims to strengthen the immune system to fight cancer cells, but they indicated a need for more information about how this

Table 2: Sociodemographic and clinic characteristics of patients.

Characteristics	Mean ± SD	Median [range]
Age (years)	58.333 ± 16.199	62.50 [20–77]
The diagnostic process duration (years)	2.166 ± 1.337	2.0 [1–5]
	n	**%**
Gender		
Female	5	41.7
Male	7	58.3
Marital status		
Married	7	58.3
Single	5	41.7
Educational status		
Literacy	4	33.3
Primary school	4	33.3
High school	3	25.0
University and above	1	8.3
Employment status		
Housewife	1	8.3
Retired	7	58.4
Unemployed	3	25.0
Actively working	1	8.3
Income level		
Medium	8	66.7
Low	4	33.3
Smoking status		
Yes	2	16.7
No	4	33.3
Quit	6	50.0
Alcohol consumption status		
Yes	7	58.3
No	3	25.0
Quit	2	16.7
Tumor type		
Lung	7	58.3
Breast	1	8.3
Prostate	2	16.7
Ovarian	2	16.7
Disease stage		
Stage III	7	58.3
Stage IV	5	41.7
Immune checkpoint inhibitors		
Nivolumab	7	58.3
İpilimumab	1	8.3
Atezolizumab	4	33.3

mechanism works. The statements of three different patients are as follows:

"I would like to receive more information about the side effects of immunotherapy, the dietary habits to pay attention to during the treatment process, how long the treatment will last, and the likelihood of success. Additionally, guidance on lifestyle changes to stay healthy during treatment would be important."

"I tried to gather information online, but I couldn't find much. It feels like a dark road with no clear end, but I guess I have no other choice…"

"It's important to be informed about what to eat and drink while using these smart drugs."

"I would have liked more explanation about the treatment. The more information I get, the more in control I feel."

3.3. Trust, Future, and Hope. Immunotherapy drugs were found to create hope and an optimistic outlook for the future in individuals with advanced cancer. When participants were recommended immunotherapy by their doctors, their perspectives on the treatment were generally optimistic and hopeful. Additionally, it was determined that patients drew support from their spiritual and religious beliefs in coping psychologically and spiritually during this process.

'During the treatment process, I always pray to God and trust in God's will. I have hopes for survival, everything is in God's hands."

"My greatest hope during the treatment process is to ask for Allah's help and healing. I pray for survival, but He knows what is best."

"When I started treatment, I believed my chances of survival had increased. I can't predict what will happen in the future, but I am hopeful."

Patients report that immunotherapy gives them a sense of trust and gratitude. Many view this treatment as a promising and innovative option in cancer therapy. Some patients believe that immunotherapy has a more natural mechanism of action compared to traditional treatments, particularly chemotherapy and radiation therapy. There is also a belief that immunotherapy has lower toxicity, making the treatment process easier. This new approach to treatment offers a different path in the fight against cancer, allowing patients to approach their treatment with more optimism.

"I progressed comfortably for a long time without experiencing any side effects, and I am truly satisfied. Maybe, without this medication, I wouldn't be alive right now."

"At least I'm in a period where my hair isn't falling out, and my appetite has returned. I can eat and drink like normal people. There are no side effects with these medications. Now I can eat, and thanks to this medication, I can have meals at the same table with my children."

3.4. Economic Problems and Financial Burden. Almost all patients mentioned financial difficulties when asked about the positive and negative effects of immunotherapy on them. Long treatment durations, ongoing expenses during the treatment process, the high cost of medications, and travel and accommodation expenses for accessing treatment are the main barriers patients face. These factors are significant challenges that make it harder for patients to continue their treatment and manage the treatment process. The statements of four different patients were as follows:

"I know immunotherapy is very expensive, but I somehow feel that I need to continue this treatment. We're financially struggling because of the high costs, but it feels like we have no other option. My spouse and I have considered using our savings or even going into debt to continue the treatment. When we add transportation and accommodation expenses, it's a very difficult situation. But still, I find hope for a longer life thanks to this medication, maybe this treatment will really give me life. However, thinking about the future is frightening because we don't know how long the treatment will last or how much longer we can endure."

"Our biggest problem is financial; this medication is really expensive. I've had 9 cycles, but I don't know how much longer I can endure (sigh). Every time, we try to find money to continue the treatment, but with these costs, I can't predict how long we can go on."

"Right now, I don't feel well at all. I'm having shortness of breath. But what bothers me most is that I don't want to be a burden to my children. I don't want my kids to be upset. I haven't told anyone because if I do, they'll have to take time off from work, and I never want to be a burden to them."

"When I should be looking after my grandchildren, my children are looking after me. I can't provide them with either financial or emotional support (crying). This really upsets me because I want to lighten their burden, but I don't have the strength."

3.5. Lack of Information Regarding Toxicities. Based on the responses from patients, it was determined that there is a lack of information regarding the side effects and toxicities of immunotherapy agents. Patients' tendency to downplay or overlook mild symptoms can be seen as a reflection of this information gap.

"I had mild redness and peeling, but I didn't pay much attention to it. Compared to the side effects I had during chemotherapy, this is nothing…" clearly illustrates this situation. "I had redness and itching on my neck, but I thought it was an allergy from something I ate. I'm not sure if it was from the medication." This statement shows that patients do not know the source of these symptoms and are unable to determine whether they are side effects of the medication or not. "My doctor gave me a lot of information about the treatment, but everything about the side effects wasn't clear." This statement reveals that patients lack information on this matter.

4. Discussion

This study explores the experiences of cancer patients undergoing ICI treatment. The research identified five main themes. These themes include patients' anxiety and uncertainty about the disease process, their need for information, feelings of trust, expectations for the future and hope, economic problems, and financial burdens, as well as gaps in knowledge regarding treatment-related toxic effects. The findings help health professionals gain a deeper understanding of cancer patients' experiences during the ICI treatment process.

Patients have emphasized the emotional challenges they face after being diagnosed with cancer and the uncertainties of the treatment process. Lack of information about the severity of the disease and treatment options has caused anxiety and concern. A cancer diagnosis is often a traumatic experience for patients. During this process, while patients worry about the seriousness of their illness, the uncertainties of the treatment process also increase their levels of anxiety. For example, Zhang and Zhang note that the uncertainties cancer patients face during treatment negatively affect their emotional state and reduce their motivation toward the treatment [9]. Hou et al. conducted a qualitative study in which they reported that lung cancer patients receiving immunotherapy experienced a lack of information and expressed concerns related to uncertainty [10]. Patients experience an increased sense of uncertainty about the future when they lack sufficient information about treatment options, which raises their levels of anxiety. The lack of information about treatment options creates anxiety and concern. For example, patients who do not have enough information about immunotherapy face uncertainty about how the treatment process will proceed and its potential side effects [11–13]. Fukuoka and colleagues highlight that the uncertainties patients encounter during the treatment process increase their anxiety levels and make it more difficult for them to adhere to the treatment [14]. Additionally, the complexity of the immunotherapy process can negatively affect patients' decision-making processes regarding their treatment [15].

The findings suggest that patients often base their knowledge of ICI treatments on fragmented and sometimes overly optimistic interpretations. The results suggest that patients often develop optimistic expectations based on fragmented sources of information, such as clinician communication, online materials, and anecdotal experiences. This information is obtained through a variety of channels, including clinician communication, online resources, and other patients' experiences. This process shapes not only expectations of treatment efficacy but also perceptions of prognosis, leading to a high level of hope that often does not fully align with clinical reality. Similarly, another study by Boulanger et al. reported that uncertainty about prognosis often coexists with strong optimism, leading to increased disappointment in the subgroup with progression or toxicity [16].

When we asked in the consultation schedule if there were any other topics regarding immunotherapy that we would like to learn about, patients responded as follows: "How will I feel during treatment? How much will side effects affect my daily life?" "Will this treatment really work for me? How will I know if it is working?" "How long will the treatment last? When will I start seeing results?" Patients expressed a strong need for practical and personalized information, particularly around the physical and emotional experiences of treatment. These findings underline the importance of patient-centered communication in oncology care. Tailoring information to address these specific concerns could improve patient understanding, reduce anxiety, and support shared decision-making. Emotional support and information are crucial for

helping patients overcome the emotional challenges they face. Nurses and healthcare professionals providing clear and understandable information about the treatment process can help reduce patients' anxiety levels. O'Malley and colleagues demonstrate that increasing patients' access to information during the treatment process improves their emotional state and enhances their adherence to treatment [17]. Additionally, support groups and psychological counseling services can help patients cope with emotional challenges [18].

The study found that patients expressed a lack of information, particularly regarding the treatment process, side effects, and concerns about the future. Similarly, a study conducted by Nicolas-Joseph et al. revealed that there are insufficient public, reliable sources to help patients obtain information about the side effects of ICI treatment [19]. In a study conducted by Hou et al., it was reported that patients with advanced-stage lung cancer have a lack of information regarding ICI toxicities [10]. Similarly, another study found that patients with advanced-stage melanoma were unable to obtain specific information about ICIs, such as potential toxicities or possible success rates [20]. In our study, patients generally reported feeling hopeful about ICI treatment and approaching it with optimism. Similarly, participants in Shuk et al.'s study were mostly cautiously optimistic; they hoped for positive outcomes but were also aware that the treatment could fail [21]. These findings suggest that healthcare professionals should inform patients about their treatment processes and potential side effects and correctly manage patients' expectations regarding the effectiveness of the treatment.

In the study, patients reported feeling guilty both for being a financial burden on their families and for being unable to support them. Immunotherapies are among the most expensive cancer treatments. Immunotherapy is typically a longer-term and more frequently administered treatment (infusions every 2-3 weeks, up to 2 years). Patients cannot have definitive information about how long their response to treatment will last, and they worry about whether the treatment will need to be repeated or whether the disease will progress, and this uncertainty can persist for a long time. Immunotherapy is a relatively new treatment option, associated with high-cost medications and limited survival data. This situation suggests that the burden of uncertainty and cost may be more pronounced for patients receiving immunotherapy compared to those undergoing chemotherapy. Various studies have also highlighted that all patients are exposed to the high costs of immunotherapy and experience financial stress [10, 22]. These findings indicate that while immunotherapy represents a significant advancement in cancer treatment, it can also lead to financial strain on patients and additional burdens during the treatment process. Increasing access to treatment and alleviating the financial burden are crucial to ensuring that this treatment method is accessible to a broader population.

4.1. Limitations of the Study. Although data saturation was reached in the study, it was conducted with a small sample group. Therefore, the findings may be difficult to generalize. This study only covers the immunotherapy process itself. The patient's preparation before immunotherapy and the process of accepting the treatment were not included in the study. It is possible that negative comments during the treatment process, if heard by the treatment team, could affect their treatment approaches, which might lead patients to report only positive attitudes. Our study was not specific to a single type of cancer. Different cancers, with their unique prognoses, treatment regimens, and patient populations, may influence how patients perceive and experience ICI treatment. Therefore, our findings may not fully capture the specific challenges and expectations related to ICI therapy in particular cancer types. Such concerns may hinder patients from sharing their experiences more honestly and openly.

5. Conclusion

This study offers significant insights into the challenges and experiences of cancer patients receiving ICI treatments. The findings reveal key themes such as heightened anxiety, uncertainty regarding the disease and treatment outcomes, a strong need for reliable information, trust in healthcare providers, and the emotional impact of financial burdens associated with the treatment. These challenges, including anxiety and uncertainty, are particularly exacerbated by the prolonged treatment process, insufficient information on potential side effects, and financial difficulties.

The results emphasize the critical need for healthcare professionals to provide comprehensive, clear, and personalized information throughout the treatment journey. It is essential that providers not only address patients' expectations concerning treatment efficacy but also manage the emotional and psychological aspects of their experience, ensuring that patients are well-prepared to navigate the uncertainties of immunotherapy. In light of these findings, future educational initiatives should focus on developing tailored programs that enhance communication between patients and healthcare providers. Such programs should equip patients with a thorough understanding of the treatment process, potential risks, and the expected outcomes, while also addressing their psychological and financial concerns. By improving these interactions, healthcare providers can help alleviate anxiety, foster trust, and ultimately contribute to more informed decision-making, thereby improving the overall patient experience and quality of care in immunotherapy settings.

Data Availability Statement

Data are available on request due to privacy/ethical restrictions.

Conflicts of Interest

The authors declare no conflicts of interest.

Author Contributions

Conceptualization: Dilek Yildirim and Ferda Akyuz Özdemir; methodology: Dilek Yildirim and Ferda Akyuz

Özdemir; formal analysis: Dilek Yildirim and Ferda Akyuz Özdemir; resources: Dilek Yildirim and Ferda Akyuz Özdemir; data curation: Dilek Yildirim and Ferda Akyuz Özdemir; writing – original draft: Dilek Yildirim and Ferda Akyuz Özdemir; writing – review and editing: Dilek Yildirim and Ferda Akyuz Özdemir.

All authors reviewed the manuscript. All authors have contributed significantly, and all authors are in agreement with the content of the manuscript. The authors take full responsibility for the content of the article. The authors have contributed to, seen, and approved the final manuscript.

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