

CELL & GENE THERAPY WHITE PAPER

Patient perspectives on CAR-T therapy in a clinical trial setting

A story of hope, challenges and recommendations for the future

Introduction

Advances in immunotherapy, specifically CAR-T cell therapy, have revolutionized cancer treatment, offering hope to patients with refractory or relapsed conditions. While the scientific and clinical aspects of CAR-T therapy are well-documented, the patient experience remains underexplored. This white paper delves into the journey of one patient with mantle cell lymphoma (MCL) who participated in a CAR-T clinical trial. The patient's journey provides valuable insights into the challenges and triumphs of cell therapy from a deeply personal perspective, highlighting areas for improvement in the clinical trial process and patient care.

A journey through diagnosis and treatment

The patient's journey began in 2016, with a life-changing diagnosis of aggressive MCL. "Within 24 hours, the disease accelerated, leading to severe spleen pain and a white blood cell count that was off the charts," the patient recalls. Initial treatments included six rounds of intensive chemotherapy and an autologous stem cell transplant, which offered two years of remission before the cancer returned in 2018. "When they found a spot in my abdomen, it was devastating", underscoring the relentless nature of the disease.

Faced with limited options, the patient embraced CAR-T therapy as their next line of treatment. "I was desperate, I didn't think I could handle more rounds of chemotherapy, and I was excited to try something new that felt like a real shot at survival."

Consenting to the clinical trial

The decision to participate in the CAR-T clinical trial was not taken lightly. The patient credited their confidence to the transparency and empathy of their care team. "The doctor wasn't overpromising; he was honest about the risks and uncertainties, which I appreciated," the patient shared. A multidisciplinary team, including a social worker and study coordinator, provided a holistic approach to preparation, discussing logistics and potential side effects while addressing the emotional toll of treatment on the patient and their family.

The patient also highlighted the importance of involving their caregiver, in this case, his spouse. “My wife and I had so many questions, but having her included every step of the way gave me the confidence to say yes. This was going to impact both of us, not just me.”

Despite the well-rounded support, the patient reflected on areas where the process could have been improved. “I wanted more information on what life would look like after the CAR-T treatment. How long would it take to recover? What happens if it doesn’t work?” While he understood the investigational nature of the therapy, these unanswered questions weighed heavily on his mind.

The treatment experience

The patient described the clinical trial screening process and apheresis procedure with a mix of apprehension and excitement. “I couldn’t help but think about my previous treatments and wonder if this might not work either,” he admitted. However, a timely reminder from his doctor shifted his mindset: “Don’t let the failure of other treatments stop us from trying this one.”

During the cell infusion process, the patient was struck by the gravity of the situation. “Seeing the crash cart outside the window was sobering, but it didn’t make me waver,” he noted. The infusion itself was surprisingly straightforward compared to earlier treatments, providing a sense of relief and optimism.

Post-infusion hospitalization brought its own set of challenges. The patient experienced fever and neurological symptoms, including tremors and mental sluggishness, which were initially distressing. “I felt like I was failing when my hand tremors worsened, but the staff reassured me that it was a sign the treatment was working,” he said.

A short stay at an apartment complex, conveniently located opposite the hospital, was organized by his medical care team to allow the patient to continue his recovery and post treatment study observations in a more relaxed home style environment.

Reflecting on the care received, the patient expressed gratitude for the compassionate approach of the nursing staff: “They knew when to push and when to back off, focusing on what I needed in the moment.”

Navigating emotional and social impacts

Beyond the physical challenges, the emotional toll of undergoing CAR-T therapy was profound. The patient described moments of doubt and fear during hospitalization. “At night, it was just me and my thoughts. I’d wonder, ‘Did I make the right choice?’”

Support from family, friends and the medical team became a lifeline. “My wife was my rock, but I also found comfort in little things, like a nurse who stayed to talk with me about her weekend plans. Those human connections made a difference,” the patient said.

Another unexpected source of strength was sharing their journey through a blog. “Writing updates on CaringBridge helped me process what was happening. It also connected me to others going through similar experiences, which made me feel less alone,” he shared.



Long-term impact and follow-up

The patient's recovery was marked by both physical and emotional milestones. "Walking with a walker was humbling, but by day 10 after discharge, I lifted it up and never used it again," he recounted. Residual side effects, such as mild tremors and occasional balance issues, remain manageable and are viewed as a small price to pay for the gift of extended life.

Long-term follow-up has been made smoother by the site's use of a portal system for communication. "It's so much easier than phone calls. I can send a message and usually get a response within hours," he explained. Convenience in follow-up testing, including local scans, has also been greatly appreciated. "If I had to drive two hours for every test, I would, but the fact that I don't have to is a blessing."

For the patient, the most significant impact of CAR-T therapy has been the ability to reclaim his life. "I've gone back to gardening, playing with my grandkids and even traveling. These are things I once thought I'd never do again."

Lessons learned and recommendations

Reflecting on the CAR-T treatment journey, the patient highlighted several key takeaways for improving the CAR-T clinical trial process:

1. Reassurance about side effects:

"If you experience side effects, it might mean the treatment is working. I wish I had been reminded of that more often," he said, underscoring the psychological toll of adverse effects and the importance of patient education.

2. Holistic patient and caregiver support:

The detailed preparation provided by the care team, including discussions about apheresis procedure, logistics and caregiver support, was invaluable. "Having my wife involved every step of the way made all the difference," the patient emphasized.

3. Accessible follow-up care:

The ability to conduct follow-up scans locally and communicate with doctors via a portal system significantly reduced the burden of long-term care. "It's not just about me—it's about making life easier for everyone, including my family."

4. Emotional support resources:

Providing access to counseling or peer support groups could help patients cope with the mental and emotional challenges of CAR-T therapy. "Just knowing there's someone else out there who understands what you're going through can be a huge comfort," the patient noted.

5. Community and awareness:

The patient's use of CaringBridge to share their story resonated deeply within their community. "I want people to know about CAR-T, but I never promise outcomes. I just share my experience and what helped me cope," he said, highlighting the power of patient advocacy.

The transformative power of CAR-T therapy

For this patient, CAR-T therapy has been life-changing. “The hope it gave me was exponential,” he shared. Since treatment, he has witnessed milestones he once feared he would miss, including the graduations of his children. “To think that’s all possible because of CAR-T—it’s overwhelming.”

The patient concluded with a message of gratitude and optimism: “Cancer is unpredictable, but CAR-T therapy has opened so many doors. It changed my life, and I say that with gratitude.”

Conclusion

This patient’s story serves as a testament to the transformative potential of CAR-T therapy and the importance of patient-centered care in clinical trials. By incorporating their feedback into future clinical CAR-T studies, we can enhance the experience and outcomes for patients navigating the complexities of advanced cancer treatments.

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