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> If companies bring in the patient perspective from the beginning, the insights they gain could make their clinical trial process go quicker and create a better understanding of how patients make decisions between different treatment options

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Claire Saxton and Lauren Kriegel of Cancer Support Community, the largest professionally led non-profit network of cancer support worldwide, discuss how cancer patient and caregiver perspectives need to be better integrated into the treatment process. This is an especially prescient issue for next-generation cell and gene therapies such as CAR-T which, as Saxton and Kreigel outline, require greater levels of patient access and associated support programs.

Can you begin by introducing yourselves and your roles at Cancer Support Community (CSC)?

Claire Saxton (CS): I am VP of patient experience and have been with the organisation for five years. For most of that time, I have led the education department, creating award-winning materials that speak frankly about the disease and allow patients and their caregivers to become active members of their healthcare team and make good and informed shared decisions.

I first started working in cancer advocacy in 1998 at a Breast Cancer Resource Center in Austin, Texas. I also worked in bladder cancer with the Bladder Cancer Advocacy Network and across all urologic cancers at the American Urological Associationâ??s Foundation, before moving to CSC to create their patient education programming.

Lauren Kriegel (LS): I am a clinical social worker in the state of New Jersey and am very new to CSC. I spent the last six years as the bone marrow transplant and CAR-T cell therapy social worker at Rutgers Cancer Institute and have now moved from the clinical setting to work with the CSC team on program development for CAR-T.

I have always known of CSC. My cancer centre worked collaboratively with them in the past, and I feel like their modality is an excellent way to connect with patients and families and help them directly.

What is the CSCâ??s mission?

CS: As the largest professionally led non-profit network of cancer support worldwide, our mission is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.

Our network of 175 locations, most of which are in the US, include CSC and Gildaâ??s Club centers, health-care partnerships, and satellite locations that deliver more than $50 million in free support services to patients and families. CSC also provides navigation services on our toll-free helpline, online support through our MyLifeLine digital community, and produces award-winning patient education programs. To inform our mission and services, CSC conducts cutting-edge research on the emotional, psychological, and financial journey of cancer patients. Our Cancer Experience Registry counts over 15,000 participants and more than a million data points on patient experiences across a range of cancers. In addition to using take that evidence-based knowledge and insights to translate them into patient services, our Cancer Policy Institute uses that evidence to look at quality, access, and clinical trial research in the US, advocating from the patient point of view and better defining patient-centred care.

There are a huge amount of new, and more targeted, oncology therapies being approved today, especially in the US. From a CSC perspective, how big is the gap between the new therapies being approved and the patient journey, and what work are you engaging in to close it?

CS: As an example, on CAR-T one of the first things that we did was a needs assessment, talking to KOLs and members of CAR-T healthcare teams across the US as well as patients and caregivers. Some very clear themes emerged, highlighting a communication gap. In many other oncology treatments, the big gap in communication is ensuring comprehensive biomarker testing, but CAR-T required a step-by-step guide. Much like bone marrow transplants, CAR-T does not involve multiple rounds of the same therapy. Each step of the process is different. Reaching step one does not mean that the patient knows what step two looks like.

A lot has been done by cancer centres and their nurse navigators, but patients need more help, especially in a big country like the US where a lot of CAR-T happens at a distance from where the patients actually live. The idea of somebody having to move for their treatment for four to 10 weeks along with their caregiver means that lots of logistical and practical information and resources are needed. Because of the overwhelming amount of information to communicate, it can be really hard for patients and their caregivers to retain it.

Additionally, CAR-T generally comes as a third-line therapy, meaning that lot of these patients are very ill or medically fragile and have already been through a lot. So many here in the US are dealing with issues of financial toxicity, because of the cost of all the lines of treatment they have had up until that point.

CAR-T therapies were first approved in the US in 2018; at what point did the CSC start receiving requests and questions from patients about their use?

CS: A small group of patients who are real information seekers and have scientific backgrounds had already begun to ask questions during the clinical trials for CAR-T. At this point, we produced a small booklet outlining in simple terms what CAR-T is; this had emerged as a real patient need to be able to explain the treatment to their families and friends.

As early as 2016, we started working on general basic CAR-T information. Then, once it was approved in 2018, we got our first big funding to produce materials that help patients cope. We have produced videos for patients outlining the process and giving them idea of what they might be facing. Another thing that came up repeatedly in the needs assessment was the fact that it is impossible to prepare a caregiver enough for when their patient is experiencing some of the neurotoxicities and severe side effects that CAR-T sometimes creates.

For one couple that we interviewed, the husband was sure that his wife was dying when she did not recognize him. We therefore developed a video on side effects; both in terms of managing side effects if they do occur and reassuring patients without side effects that this does not mean that their treatment is not working.

There is a certain amount of misinformation around CAR-T as a one-time miracle cure, when in fact that is not the case for many patients. How have you had to work to manage patient expectations around CAR-T?

CS: People always invest hope in new technologies, which has pros and cons. When you talk to patients, if they have had severe neurotoxicities, they often do not remember that period at all. However, this same period can be traumatic for caregivers seeing their loved ones in the ICU, perhaps failing to recognise their own family members.

Therefore, our needs assessment concluded that we had to set expectations for very different perceptions of what those side effects look like, because in general, they are short term. The long-term side effects that most people have after coming out of CAR-T cell therapy are in fact from their earlier lines of therapy.

LK: There is a good level of education within the medical community but sometimes that level of education is not there for the average everyday person. In my previous position, when we started our CAR-T program, we had to have a contingency plan for an extremely high level of patient requests. It is not widely known that CAR-T is only for certain diagnoses and only to be used once frontline therapies have failed.

CS: Through telling patient success stories, it cans seem like CAR-T is a miracle cure for all. However, it will only work with a specific set of patients and probably only have long-term positive impact for a third of that cohort. Therefore, while it is incredible to those patients where it succeeds, there are also those patients who relapse or who do not get a good response. We do not tend to tell those stories. Therefore, when we have worked with pharma companies on CAR-T awareness campaigns we have been very clear on the need to manage expectations.

How good a job have company sponsors done in communicating the journey that CAR-T patients and their caregivers go through?

LK: I think the medical teams and the pharmaceutical industry are doing a good job. The problem is, no matter how clear anyone tries to be about what neurotoxicity looks like, it just does not hit the same until you walk into a room and see your spouse of 30 years not be able to tell you what day it is or where they are. A doctor can sit down and tell you this is what neurotoxicity looks like and yet it somehow still does not fully prepare a loved one for seeing it in person.

For other cancer treatments, a lot of work has been done on the utilisation of real-world evidence (RWE) to create a more patient-centric drug discovery process. What lessons can be taken from these other treatments and be extrapolated into CAR-T, a relatively new field with a lack of RWE?

CS: With our needs assessment we collaborated with centres that had taken CAR-T patients through the clinical trial process and talked to patients, caregivers, and KOLs who had been working with the technology for several years. We also talked to institutions that were just starting to offer these therapies. We knew that the institutions that had been part of the clinical trials already had systems in place to help with that navigation and education, but as it went to additional centres and grew, that there would be more resources needed to help navigate and educate patients. The more informed the patient and caregiver is, the better that they can be an active part of their healthcare team.

Lauren, can you introduce the work you have been doing on the CSCâ??s CAR-T support program?

LK: We have developed a thorough and extensive CAR-T guide to help patients and caregivers each step of the way through the process. Additionally, we have discussion boards that I, or another licensed clinical social worker, monitors that allow people to ask questions of others going through something similar, and share experiences and tips. Moreover, we are creating a dedicated helpline for CAR-T questions and inquiries and are launching a three-part webinar series this Fall, aimed mostly at caregivers, but patients as well.

The first two webinars are psychosocial; the first focused on managing stress during the CAR-T process and the second around living with uncertainty. The final webinar in the series is going to be presented by an advanced practice nurse in the CAR-T field talking about side effects, creating a better understanding among caregivers, and building up the resource base on which they can draw.

Is part of your work also focused on helping patients that want to enter clinical trials for CAR-T?

LK: Absolutely. One of our helpline staff is a specialist in clinical trials. A couple of weeks ago, I received a call from someone who was next in line for a CAR-T clinical trial and then, unfortunately, the trial closed and he was desperate to find a new trial. We were then able to connect him with our clinical trial specialist who was able to walk him through the process, step by step.

Affordability is a huge issue in the US, especially for costly therapies like CAR-T which are not necessarily covered by social insurance programs. What work do advocacy groups like CSC engage in to help patients with cost of care?

LK: In addition to our clinical trial specialist, we also have a financial navigator who specializes in these issues. She works with patients who are uninsured, underinsured, have policies that do not cover enough, or have high-out-of-pocket expenses, to dive deeper into whether they can get better coverage and, if not, whether they can find funding or assistance.

CS: Financial toxicity is such a big issue in the US that every patient advocacy organisation touches on helping with cost of care. However, unfortunately, groups like CSC do not have all the answers.

Drawing on your experience in the field, what game changers would you like to see in the CAR-T patient journey?

CS: The first is more access. CAR-T will not move out to every cancer centre out there, but a greater number of centres offering CAR-T will help in terms of fewer patient having to relocate. That is still always going to be an issue unless the process changes to a point where it could be administered in the community setting.

Moreover, the more support that is available to patients and caregivers the better. This is especially true for patients without a readily accessible caregiver, those whose insurance will not cover the treatment, and those who simply cannot afford to take 10 weeks off to receive it. Additionally, the possibility of CAR-T being offered as an earlier line of treatment would also be game changing.

LK: As a big advocate for mental health parity, I would love to see increased access to mental health services for people going through CAR-T. Speaking with a mental health professional before undergoing such a procedure would be enormously helpful to ensure that patients are as prepared as possible for the emotional impact.

What changes would you like to see in the way in which pharma companies engage with patient advocacy groups?

LK: Given my background as a social worker, I would love to see pharma companies opening up funds for assistance with things related to the treatment. In my experience, pharma companies have patient assistance programs that usually help solely with the cost of the medication. However, sometimes they need lodging, transportation, and help with other items.

CS: I have worked with some pharma companies who are ahead of the game and really involve the patient point of view from the beginning of their projects. However, there are also companies that do not think about that until they are about to go to market or launch an awareness campaign. Additionally, many start-up companies do not begin to think about patient-centricity until they are acquired by a larger firm with the infrastructure and resources to invest in it.

If companies bring in the patient perspective from the beginning, the insights they gain could make their clinical trial process go quicker and create a better understanding of how patients make decisions between different treatment options. Having patient advocacy groups and patients and caregivers themselves represented on advisory boards can help ensure that the therapy is designed for the whole patient and not just for the cancer cell.

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