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04.11.2021

Tags: Singapore, Asia-Pacific, Novartis, Patients

Angeline Ho gives an overview of the patient advocacy landscape in Asia-Pacific, why an Asian model of patient engagement – distinct from those in Europe and the US – needs to be developed, and how Novartis has been working with patients in the region around its CAR-T therapies.

How did your entry into the relatively new field of patient engagement come about?

My background is in communications and public relations which involves working with different stakeholders, learning about their interests and thoughts, and figuring out how to collaborate with them. I have been with Novartis since March 2018 and am now part of the Cell and Gene team as the communications and patient advocacy lead for Asia Pacific. This role allows me to use my skills to engage with patient leaders, individual patients, and patient organizations to understand their needs, priorities, opinions, and motivations. As the patient advocate within Novartis, I also work with internal stakeholders across multiple functions including medical affairs, market access, operations and the commercial team to share patient insights which helps drive better outcomes that are meaningful to patients.

What would you highlight as the particularities and key trends of the very diverse Asia-Pacific region?

Asia-Pacific is a very large region, holding approximately one third of the global patient population, and it is still growing. The cancer burden in Asia-Pacific is also large, but there are significant disparities between the region’s wealthiest and poorest economies in terms of public healthcare expenditure, infrastructure, and levels of training among healthcare professionals. This makes working in APAC challenging but at the same time very exciting, dynamic and rewarding with many opportunities that can make a difference in the lives of patients.

Increasingly, cancer patients in APAC are becoming more well-informed with the prevalence of the internet and social media, often using these online resources to get more information about possible treatment options. In some cases, patients travel to other regions or countries where there are more medical expertise and treatment options.

For many patients today, the focus of the treatment outcome has shifted from survival alone to also include quality of life. Doctors and patients may have different treatment end goals so it is always important for patients to let their voices be heard. What is an issue for the doctor may not necessarily be an issue for the patient, vice versa.

Additionally, in many Asian cultures, being sick is still a sensitive topic. In some cultures, even shameful. Patients in this region may be reluctant to let others know that they had cancer because this may affect their chances at employment, marriage, and how they are perceived as an individual. Therefore, sometimes it is difficult to get patients to share their stories and lived experience.

Does that reluctance to share stories have an impact on building support communities for diseases?

Definitely. Patients that are willing to come and tell their stories are few and far between and there is generally a lack of representation in media and patient resources, making getting information more daunting. During one of our patient advisory boards, some patients shared how it was difficult to find content such as Asian recipes during cancer treatment or people who had similar cultural backgrounds to share what they are going through. While it was easy to find resources from the Western world, finding content in local languages with stories from the Asian community was not easily found. This made patients in Asia feel more alone in their journey and not get adequate peer support. Besides hearing from their treating physicians, patients are also keen to hear from similar patients who have gone through a similar cancer journey. Thus, it was important for us to understand the patient journey from patients in Asia and ensure our programs and patient resources reflect their realities and better cater to their needs.

The taboo around illness and limited capability and funding of local support groups may also be the reason why there are countries in the region with patient organizations and others without. We want to offer help wherever we can and help advocate for patients and their unmet needs. There is no shame in having and fighting cancer. We also believe in the power of the patient’s voice and story. Every cancer patient who steps out to share his or her story is a sign of great courage and strength, often inspiring families and many others in their own battle with cancer.

Given APAC’s distinctive characteristics, is there a need for a very different model of patient engagement to that seen in Western countries?

Yes, it is important to use a different model of patient engagement that is more suited to the needs and unique values of patients in Asia. Key topics to consider include the multi-racial, multi-lingual and multi-cultural context in Asia, understanding the impact of culture on health-seeking behavior, considering values like filial piety, modesty in attire, respect for seniors, respect for authority and the issue of “face”. For example, in western cultures, more emphasis may be placed on a patient’s autonomy. In contrast, in Asia, seniors with cancer may not even know the diagnosis, as their family members may have requested the doctor not to reveal the diagnosis to their loved ones. Patient engagement models should be based on local patient insights from their respective cultures. It is not a one-size-fits-all approach.

What is the situation with Novartis’ CAR-T therapy in APAC today, especially considering the differing levels of healthcare system development in the region?

It is very encouraging to see such innovative treatments coming to our part of the world. At Novartis, we are committed to helping every patient access the best treatment option for their disease. Our CAR-T is now approved in Singapore, Hong Kong, South Korea, Australia, Japan and Saudi Arabia. For countries where CAR-T is yet to be approved, a key component of our plan is to prioritize countries with regional centres of excellence treatment centres, such as those in Singapore, Hong Kong and Saudi Arabia who have the right capabilities and capacity to receive patients from the neighbouring countries. Our goal is to increase awareness of the disease and treatment options available for patients. Patients have the right to know that there are now newer and more effective treatments available in the region that can potentially help them treat their disease for life.

It is important to note that CAR-T is currently approved for orphan populations in the third-line setting. This means that these patients have relapsed or have refractory diseases; in other words, those that have limited options left after not responding to current standards of care. We hope to inform patients that there are innovative treatment options available in the region, without the need to travel to the US or Europe to seek the same treatment. Before CAR-T came to Asia, patients had to travel to the western world to access a certain level of care if needed and if they could afford it. Now that we have CAR-T in the region, it is important to share that it is approved and available. For approved products, patients can expect the same CAR-T quality level as that approved in Europe or in the US. I am also very happy that Novartis is manufacturing our CART therapy in the region.

We must stress that not all patients are eligible for CAR-T and patients should always clarify and seek medical advice from their treating physician or a healthcare professional. In addition, there are different considerations with CAR-T; many of these patients are very ill, and sometimes they are not even fit to take a flight to seek treatment abroad. COVID – both in terms of the risk of patients catching it as well as quarantine and travel restrictions – has added yet another layer of complexity in accessing treatment abroad.

What impact has reimbursement played for CAR-T treatment referrals in APAC?

In countries like Hong Kong, Japan, Australia and Saudi Arabia, CAR-T is approved and fully reimbursed by their local governments. However, in Singapore, South Korea and for patients travelling to seek treatment abroad, CAR-T is not reimbursed and often needs to be paid for out-of-pocket. Therefore, many patients rely on their private insurance for coverage. As CAR-T can only be administered by qualified treatment centres, a key component of our plan is to prioritize countries with regional treatment centres of excellence such as those in Singapore, Hong Kong, and Saudi Arabia who have the right medical expertise, experience and capacity to serve both their local population and patients from neighbouring countries.

How would you describe the level of awareness of patients and patient groups around topics like CAR-T?

I would say awareness is still relatively low in Asia among patients, patient groups and even physicians. More can be done to help patients understand the breakthrough science of this treatment and the impact it might have in improving and extending their lives.

It is important for the patients and decision-makers to really understand the value that CAR-T brings to the patient and a healthcare system; it changes the system of taking medications for long periods of time versus a treatment that is a one-time infusion. There is value in achieving quality of life sooner, being able to go back to work and do what you love, not only for the patients but also for the caregivers. It must be remembered that fewer treatments and fewer patients visiting the doctor so frequently would also be a relief for the health system.

These one-time, transformative therapies, therefore, require a big shift in thinking about medicines. They will not and should not fit into conventional frameworks of evaluation.

When it comes to accessibility or affordability, we must focus on patients and help them understand what kind of potential life-long value they are getting, and on decision-makers, and how valuable it is for the country and the healthcare system. Once people start to see the value, they are in a better place to make an informed decision.

How is the current situation around data collection and sharing that you most commonly observe?

In most post-treatment data, the patient’s identity is not revealed and in such cases, patients may be more receptive to sharing and participating in data collection. It is also a matter of designing the data collection process so that the burden of participation for patients is reduced, such as by eliminating unnecessary clinic visits.

Data collection is very important for innovative treatments as it allows us to show different authorities how a treatment makes an impact not only in the clinical trial setting but also in the real world; how patients are performing and how the treatment is contributing to people living longer and healthier lives.

As a patient advocate, what do you think will be the game changers and really move forward the adoption of CAR-T?

Increasing the level of awareness not only amongst physicians but also patients is going to be key. To do this, we are working closely with our treatment centres and the patient organizations in the region such as Viva Foundation and Lymphoma Coalition Asia, to gather patient insights and collaborate on educational opportunities for both physicians, the patients and the public. We are also developing more online resources such as a regional disease awareness website which will host patient stories from Asia and be available in the different Asian languages.

Affordability is also a key aspect and something we need to keep on working with different stakeholders and payors to build understanding around the value of the treatment and the impact it can have on healthcare systems, society at large and the patients’ quality of life.

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