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Cancer really needs to be integrated into the general mindset of all doctors, not only oncology specialists

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Dr. Saunthari Somasundaram walks us through the NCSM's mission to raise awareness on cancer prevention and early diagnosis in Malaysia. She details the need for more government support to make cancer education a pillar in healthcare and discredits the idea that care only includes treatment and cure.

Could you please introduce yourself to our international audience as well as the key activities and responsibilities of the National Cancer Society of Malaysia (NCSM)?

Founded in 1966, the National Cancer Society of Malaysia is the oldest civil society organisation for cancer in Malaysia. Historically, in the 1960's, cancer treatment was only available in one hospital, Hospital Kuala Lumpur. NCSM's first mission was to further develop cancer services at the hospital, especially looking at other aspects outside of treatments. For 53 years, the Society developed its services and now relies on three main pillars: education and advocacy, care, and support.

The education and advocacy missions are meant to increase awareness of cancer for the general population and healthcare professionals. Cancer really needs to be integrated into the general mindset of all doctors, not only oncology specialists. Our care segment goes back to the roots of NCSM. Indeed, in the late 1960's, the Society worked with the Institute for Medical Research (IMR) to start the first cytology centre in the country. The NCSM can be seen as a unique organisation as

it has its own clinic services with women's health and cancer screening centers as well as a nuclear medicine centre. The first mammographies in Malaysia were also initiated by the NCSM. Prevention and early detection are the DNA of the NCSM and lot of work still has to be done. Finally, the last pillar is support. The NCSM started the first peer support counselling and cancer network. We developed a help line, support groups, and our next plan is to build a network of supportive care and rehabilitation that is needed to provide a more holistic approach towards cancer.

What are the society's current areas of focus?

The two main areas of focus are education and support. Regarding supportive care, there is the need for more integration in the entire healthcare system. For example, when talking about cancer care, people only focus on what the doctor is prescribing as treatments, but in terms of compliance and wellbeing, it goes way beyond going to get the medication. Unfortunately, in Malaysia the mindset is still set on care means therapy, meaning that all resources are allocated to therapies and treatments while care (physical therapists, nutritional therapists, cancer nursing care) is left apart. There is nothing done at the moment to accompany patients through the transition in their cancer journey from the hospital to home. The NCSM is advocating to fill up those gaps thanks to its support network or through the helpline operated by dedicated nurses well aware of these issues. The NCSM is also trying to ensure conformity in terms of support between the rural and urban areas, and makes sure that wherever you stand in Malaysia, support is available.

A bit more than a hundred days ago, a new government and Minister of Health were elected. What is the NCSM excepting from this new Ministry?

The main action NCSM is advocating to the new government is the adoption of a National Cancer Control Plan for which we have been fighting for more than a decade. The plan is crucial and integral to better address cancer in the country. The previous National Cancer Control Plan was a document used internally but it was not shown to the general population and stakeholders. Moreover, even though it looked really good on paper, the previous government did not allocate resources to implement it. Last year, the plan was finally made public, but the issue remained the same: the plan was well written, but no decisions were made on how to implement or finance it. From other countries, we know that having a well thought-up National Cancer Control Plan integrated within the government, private and public industries, and the civil society has a positive impact on the economic burden that cancer represents in the country. In 2017, WHO came up with

resolutions on cancer and one of them was that all countries should have this implementable and resourceful Cancer Plan. Reaching this stage cannot be done overnight. It is a challenging step by step process but plans and clear policies can ensure that all public and private stakeholders can work towards it together.

The NCSM is also expecting localized data from the government. It is a necessary step to be able to target the right patients and treatments. Indeed, due to the diverse pool of Malaysian patients, relying only on research from on other countries won't work. Today, minimal data is available in the country which makes it complicated for us to get better at treating our patients and see areas where improvement is needed.

The number of cancer cases is expected to grow by 54 percent in the country by 2025. What are the main challenges impacting the oncology field in the country?

This increasing number of cancer cases appearing in the study is only based on the rising and ageing population of Malaysia and does not take lifestyle changes into account. However, we have to bear in mind that Malaysia is rising economically, moving from a middle-income country to a high-middle-income country. This switch comes with different lifestyles that leads to more obesity, increase of diabetes, and other health aspects that all together increase cancer risk. Therefore, we are unfortunately excepting a much higher number of cancer cases.

We believe the National Cancer Control Plan will help us map the needs of the country and prioritize them. Indeed, we cannot only focus on the treatment of cancer, as the health system won't be able to cover it. In Malaysia statistics are available but they do not reflect the true reality of the country. For example, on paper, Malaysia is a middle-income country with brilliant universal healthcare, a high number of hospitals, access to the latest treatments and with one of the highest ratios of radiotherapy services to population. However, when looking at the reality, there is a lack of equity in the country when it comes to cancer care and it has to be addressed as most services are dispensed in urban areas leaving some states in the country without any radiotherapy services.

Malaysians citizens seem to be rather unaware of the importance of screening and preventive care for their health. What would be necessary in your opinion to further increase prevention in Malaysia and what role would NCSM take in this area?

When looking at prevention and early detection of cancer, we do not know what the exact resources committed to cancer control, and what is spent on treatment and on prevention. Despite the lack of official numbers, studies have shown that less than two percent of national healthcare spending is spent on cancer prevention and early detection. When looking at the Non-Communicable Diseases (NCD) Plan, it focuses on heart diseases and diabetes but not on cancer, even though it is one of the top four NCDs in the country.

In this regard, the NCSM is advocating for the idea that cancer needs to be addressed more widely in clinics and by healthcare professionals. We have started a national program to increase general practitioners' awareness on cancer, so they can integrate it into their daily practice, as it has been found that doctors do not mention cancer to their patients unless the latter ask about it first. The general population relies on and trusts their healthcare providers to educate them and give them the right information, so doctors omitting cancer during consultations is a serious issue.

Moreover, the government spends a lot of resources in cancer treatments, leading the population to believe that they need to get a treatment. However, a complex mix between education and behavioural change is needed for patients to understand that cancer can be prevented. To do so, the government can use school awareness programs, preventive education and policies to change the general public mindset at a young age to avoid any bad habits. For example, the NCSM is involved in tobacco prevention for which we go to schools to help teenage smokers quit. There are some successful stories in Malaysia such as the National Vaccine Program, showing that if the government is supportive, preventing cancer. Cancer control requires political will and the courage to face the challenges ahead, especially when confronted to push-backs from stakeholders.

The NCSM is partnering with different institutions in the country, mostly in the aim to bring more knowledge and expertise to healthcare practitioners and patients. What are you excepting from these collaborations?

The NCSM is indeed working with the pharmaceutical industry on the idea of providing holistic care. The industry does realise that doctors are not the only decision makers in Malaysia. Patients have the right to be up-to-date with advances in treatment, so patient-centric care is very important, and Malaysia should move towards it. Doctors and the pharmaceutical industry have the responsibility to ensure that patients have access to information about treatment in a clear and understandable way. They need to be aware of what each treatment involves in terms of cure, and also in terms of quality of life. Many patients think that spending more money on treatments

means getting a better solution which is not necessarily true as it might not answer their personal need as well. Patients and doctors have to look at different outcomes considering that some patients might choose their quality of life over their length of life.

We want these collaborations to help the NCSM to reach its goal of ensuring that patients have access to good cancer care everywhere in the country by having all stakeholders working together towards similar goals.

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