Going beyond the killer disease, this Cancer Day

Sudha Nambudiri, TNN | Feb 4, 2015, 02.24AM IST

KOCHI: They battled a killer disease and yet continue to live with the uncertainty of possible recurrence and an unspoken stigma.

The issues faced by cancer survivors are many - mostly unaddressed. "Caught up with treating patients, we seldom go into issues they face once cured" -this is how many oncologists in the state react.

Doctors say that about 30% of cancer patients survive the disease. Of this, about 4% are children or adolescents. But there is no data or studies which look into their health or other issues, authorities say.

"Unfortunately, there is no systematic study of their psychological issues or long-term health problems.

Even if we do inquire, it is only on an individual basis," said Dr Kusumakumary P, professor and head, department of paediatric oncology, Regional Cancer Centre (RCC), Thiruvananthapuram.

In fact, many children are reluctant to attend groups catering to cancer survivors once they grow up. "Once they start attending college or going to work, they become reluctant. So we ask them to return only if they have health issues."

Their quality of life too takes a beating with friends and relatives constantly inquiring about their health and possible relapse.

"Honestly, we don't even know their issues."

It is difficult for them. Living under a very strict regime for the first five years when formal education is not yet complete, managing careers that get interrupted, prospects for marriage and having children are all major concerns," said Dr K Pavithran, head of medical oncology, Amrita institute of medical sciences.

He suggests that at a policy level, a follow-up care plan should include surveillance to detect
recurrence and late adverse effects, interventions to manage ongoing problems as well as age and sex-appropriate healthcare.

Dr Narayanankutty Warrier, medical oncologist at Malabar Institute of Medical Sciences, Kozhikode, opines that lack of supporting medical teams including doctors and counsellors has led to a gap in addressing the issues. "The patients will not speak to anybody except their doctors. They don't even open up to counsellors. Ideally, such teams would help us collect data to support research. We can't transfer such responsibilities which reduces possibilities for solutions," he added.

The latest data from RCC, Thiruvananthapuram, indicates a 14% increase in the number of cancer patients in the state. As many as 14,985 new cases were registered during 2012-13. The total number of cancer cases is 2,08,926 and review cases are 1,93,941 patients at RCC alone, which is a cause of concern. Oncology experts say it is time the state formulated a policy for cancer survivors, especially young ones.

RCC director Dr Paul Sebastian admitted that the issues of survivors are yet to come into focus. "Most importantly, we need to carry out studies on paediatric cancer survivors in the state."