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Editorial Commentary

Chronic myeloid leukemia: An Indian scenario

Chronic myeloid leukemia (CML) has many firsts: It is one cancer linked to an acquired structural chromosomal anomaly. In addition, it is the first disease to have a drug synthesized to switch off the elaboration of the gene product that drives the disease. A veritable success story, it changed our line of thinking about the mechanistic basis of cancer and search for cures. It drove a whole generation of *in silico* synthesizers, a frenzy to find driving mutations in several cancers, accurate methods to monitor response, and finally feel "comfortable" at converting cancer into a chronic livable disease.

Why worry about it in India? It is to document that the disease is more common than in the West. The innovator offered the drug "free" to those who could not afford it in India. The offer was irresistible. Here is a new form of drug delivery - "targeted" therapy. It spared the rest of the body from "indiscriminate" killing and horrific side effects of chemotherapy. It was indeed very appealing to both patients and doctors.

In addition, most of us are curious to see whether what is true in the Western world holds true in the East. We wish to analyze our patterns of presentation, often harping on the fact that patients present "late" and hence, our results are inferior to the West.

We are also curious to analyze whether the bias against Indian-made drugs is indeed true – since our drugs are cheap, they must be inferior! The answers were always there – we simply ignored them!

It also spurred activity in a hitherto silent area – molecular diagnostics in oncology. Now, there are Indian-made custom probes. However, we are still far from manufacturing a thermal cycler! Until then, the cost of molecular diagnostics in India is unlikely to come down. Moreover, our monitoring efforts will remain far from satisfactory.

The summary of data published from India on CML makes very interesting reading. Several points glare out: we have a younger population. This is unfortunately unverifiable against any documentation of age. Most patients do not have any proof of age. The traditional ration card, voter identity card, or the Aadhar card are essentially inaccurate documents. A self-declared notarized affidavit suffices to prove ones age in India!

Majority of the patients present only when symptomatic. If one analyzes the reasons why patients at all come to Indian hospitals, it is only desperation that drives them. The hemograms in most of the diagnostic laboratories are substandard. Automated counters are notorious for missing the differential by a mile, and the over-reliance on laboratory rather than clinical clues to diagnosis is a deplorable trend in clinical medicine. Hence, CML is often seen and treated as "malaria," tropical splenomegaly, or portal hypertension, for a substantial duration, before some alert clinician stumble on the diagnosis. Hence, while logistics contributes to delayed presentation, several medical reasons exist, as elaborated.

Monitoring is erratic due to nonavailability of test centers. This raises the need to build capacity in local medical college hospitals rather than centralized "coupon" testing offered by the pharmaceutical industry. The International CML Foundation has helped select individual centers in India in this capacity building. However, these few centers are unlikely to meet the need of the large variegated population. The reason why several of us do not test is perhaps more to do with what next. A test for purely academic reasons perhaps makes good the knowledge gap, but does not offer any solace to the patient or doctor, until the alternatives are made affordable.

Several states, starting with Andhra Pradesh, now offer imatinib, free to all nonaffording patients. However, it is for the oncology community to lobby for testing on a locally acceptable standardized schema.

What is perhaps important is that we need a software program for the computerized database. It must be singularly easy to create and implement – the Nimmagadda Foundation and the National Cancer Grid could take the initiative. I feel that patients must be given access to enter data and view their medical records – this will create the much-needed impetus to stick to a monitoring guideline and treatment protocol.

Interestingly, while the patient assistance program builds a volunteer body, those not on it will be excluded. Perhaps, it is time the patients and their caregivers join hands to drive the future of drug pricing, testing, and research, especially societal and economic costs.

The most laudable feature of the summary is that it is timely, points our lacunae, and prompts us to take action. Indeed, the authors could well visit the arena in about 5 years to see the impact of this summary and editorial.

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