From Australian Doctor: 20th February, 2012

Less supposition and controversy needed

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I am the "famous patient" discussed by Associate Professor Ian Haines and Professor Ray Lowenthal in a hypothesis that, despite my refusal to agree to publication, has appeared in Internal Medicine Journal, has been commented on in ***Australian Doctor*** and then added to by an opinion piece from Lowenthal. The claim is that I did not recover from secondary osteosarcoma way back in 1978, but only from TB.

I refused permission on two grounds.

First, the hypothesis is not credible. Haines and Lowenthal stated "exceptional claims require exceptional evidence". Haines and Lowenthal have not provided this; quite the opposite.

Second, I sought to avoid becoming unnecessarily embroiled in a public controversy over my personal case history. While appreciating I am something of a public figure, this breach of anonymity and confidentiality over a flimsy hypothesis in my opinion is deplorable.

To be clear, Haines and Lowenthal failed to take account of three crucial pieces of evidence.

1.They did not discuss my case with my doctors. They did not access their clinical histories or the originals of the extensive diagnostic investigations that were carried out.

If they had spoken to my treating doctors, they could have clarified the basis for their initial diagnosis and how, years later, they stand firmly by it.

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My chest physician, a TB authority, states “one can get calcification directly from TB… but nothing remotely of the appearances of your calcification”. The clinical picture fits osteosarcoma, not TB, and is supported by extensive investigations.

2. The authors discount the histology of a large boney mass removed from my left lung following pneumonectomy in 2004. The report states “foci of coarse sclerotic and heavily calcified bone which are devoid of viable osteocytes. The latter appearance in particular is recognised as a change which may occur in osteosarcoma after chemotherapy."

3. The authors have overlooked the significance of my having received powerfully immunosuppressive chemotherapy in 1976 because my condition at the time was actively advancing. To give strong chemotherapy to a patient with widespread, active TB would almost certainly result in miliary TB and a rapid death. By contrast, I experienced no significant side effects.

Finally, there are four significant errors in the timelines presented by Haines and Lowenthal. The implication of the timelines they have chosen to use is that there was no response to the chemotherapy treatment given from October to December 1976 and that this supports their hypothesis that I had TB rather than secondary cancer. This supposition is clearly disproven by the facts.

This is also significant as I have spent 30 years using lifestyle-based, self-help techniques and group therapy to assist people affected by cancer. I have always recognised that chemotherapy played some part in my recovery, have always worked within an integrative medical context and been fully supportive of effective medical treatments.

There is widespread support for a more integrated approach to cancer management and we need less supposition and controversy, along with more good quality research.