

14/01/2012 Letter to the Editor Internal Medicine Journal

Re the online publication from 21 12 11: Personal Viewpoint: Hypothesis. The importance of a histological diagnosis when diagnosing and treating advanced cancer. Famous patient recovery may not have been from metastatic disease. I. E. Haines and R. M. Lowenthal.
Accepted article DOI: 10.1111/j.1445-5994.2011.02686.x

I am "the famous patient" discussed by Haines and Lowenthal in a hypothesis that despite my refusal to agree to publication has appeared in Internal Medicine Journal. I am disturbed that the Journal would agree to publish this speculative case report without permission of the patient (myself). Indeed, the Medical Journal of Australia refused to publish the report on these grounds. I wonder if the authors of the report divulged this rejection on submission of the report to your Journal, and what the peer opinion of other major journal editors would be about publishing case reports where the subject of the report had expressly refused permission for publication. For the record, I refused permission on two grounds.

Firstly, the hypothesis is not credible. Haines and Lowenthal stated "exceptional claims require exceptional evidence". To contradict the opinions of my treating team of physicians and the extensive documentation of my case 35 years after the event, one would think required strong evidence indeed. Haines and Lowenthal have not provided this.

They did not discuss my case with me or my doctors, nor did they examine their extensive records. My original diagnosis of secondary osteogenic sarcoma, later complicated by TB was well established, is well documented and is accurate. The hypothesis that I had TB and not secondary cancer is speculative and is based upon supposition.

In a separate letter to this Journal, my wife, Dr Ruth Gawler has pointed out three crucial errors in the Haines and Lowenthal's paper that highlight some of its deficiencies.

Secondly, I sought to avoid becoming unnecessarily embroiled in a public controversy over my case history. In the event, the case found its way onto the front page of a number of major newspapers around Australia and I understand it has been circulated quite widely overseas. While appreciating I am something of a public figure, this breach of anonymity and confidentiality over a flimsy hypothesis is in my opinion deplorable.

Finally, I do need to set the record straight as there are four significant errors in the timelines presented by Haines and Lowenthal.

1. They state that in October 1976, "lumps appear on anterior chest wall". In fact, I have a series of photographs taken monthly during the time of these "lumps" being present and they were at their largest at this point in time.
This is corroborated by the records of my treating oncologist Dr I Burns that state on the 13th August 1976 "the masses on the anterior aspect of the chest wall have increased in size", and on 2nd September "it measures 14cm in diameter".

It maybe helpful to explain that one particular photograph of my chest wall, taken at the time of commencing chemotherapy in October 1976 and widely reproduced in the medical and popular press, when re-photographed for a TV program many years ago was mislabeled as coming from October 1977. My ex wife, Grace Gawler, used this mislabeled photo to question my case in the MJA in 2010¹. This error was refuted by Prof G Jelinek and Dr R Gawler in a letter published in the MJA along with that of my ex-wife. Unfortunately, Haines and Lowenthal acknowledge having consulted my ex-wife rather than myself or my treating doctors when putting their timelines together and have perpetuated this error, along with those that follow.

2. They state that in December 1976 "no improvement and chemotherapy ceases". Burns letter

of 16th December 1976 states “The mass on his chest wall has decreased in size from 13cm x 13cm to 10cm x 10 cm”. While there had been some improvement to this time, and despite warnings of rapid rebound if chemotherapy was stopped at this point, I elected to cease treatment. This is a crucial point as I have spent 30 years using lifestyle-based, self-help techniques and group therapy to assist people affected by cancer. I have always recognized chemotherapy played some part in my recovery, have always worked within an integrative medical context and been fully supportive of effective medical treatments.

3. They state that in January 1977, “Lumps on chest wall continue to enlarge while in the Philippines”. The sequence of photographs demonstrates a slow but steady reduction.
4. They further state that in July 1977 “Anterior chest wall lumps significantly larger”. At this time, the sequence of photographs show the lumps continuing to resolve. The implication of the timelines used by Haines and Lowenthal, 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. Furthermore, if they had been correct and I did have widespread, rapidly advancing TB, would not high dose chemotherapy have caused a significant adverse reaction and possibly death? By contrast, my condition and blood counts improved steadily throughout the treatment. A real concern with this paper is that the controversy surrounding it may result in some needy cancer patients and their families being led away from valid lifestyle-based, self help and support options being offered by many individual practitioners and organisations. 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.

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References:

1. Gawler GO. Cancer patients at risk from inaccurate clinical reporting in a high-profile alternative treatment story: comments and corrections. *Medical Journal of Australia*. 2010;193:371-2