BOOK REVIEW

Don’t Fence Me In: Leprosy in Modern Times

Tony Gould has made a valuable contribution to the history of leprosy with his extremely interesting and readable book. His judicious selection of narratives told through outstanding and often quirky personalities provides an historical and geographical overview of the story of the disease from representative points of view. Structurally, the book is masterful in its management of an overwhelming subject: from New Brunswick in the 1820s, Norway in the 1830s, Molokai in the 1840s, the British Empire, Japan and Russia in the late nineteenth century; and then Culion, in the Philippines and Carville, in Louisiana, USA, from the turn of the nineteenth century, into the mid-twentieth century. Facets of the continuing story are also told with historical highlights through the lives of Armauer Hansen, Damien de Veuster, Robert Louis Stevenson, Jack London, Wellesley Bailey, Hannah Riddell, Kate Marsden, ‘Ned’ Langford, Victor Heiser, Leonard Wood, Windsor Wade, John Ruskin Early, Leonard Rogers, Stanley Stein, Peter Greave, Peter Hall, Gordon Ryrie, Paul Brand, and Stanley Browne.

The last two chapters bring the book to a thoughtful conclusion. The second last chapter focuses on Nepal, and asks us to consider the persistence of leprosy and the need for rehabilitation in conditions of poverty within the context of the complex politics of leprosy control today. The final chapter ‘A Kind of Closure’, completes the circle that opened with the ghastly treatment of the poor people at Tracadie, New Brunswick, in 1844, by telling the story of restitution and financial compensation to the residents of the Japanese sanatoria through Dr Fujio Ohtani’s witness to the Japanese court in 2001.

In addition, Gould’s explanations of medical understandings of leprosy are also brought full circle. He begins the book with a clear and comprehensive explanation of the mysteries, myths and popular representations of leprosy throughout history, as well as the differing cultural, but equally stigmatizing, responses to the disease. In addition, he provides a clear description of changing medical perceptions. Then in the final chapter, he ends with a provocative but intelligent consideration of what may yet be learnt about leprosy, even managing to touch on the intriguing possibility that the fundamental premises of leprosy may yet be re-examined.

But even this description fails to do justice to the ground that Gould manages to touch upon. The chapter on Stanley Stein not only does justice to the extraordinary personality and dynamism of a ground-breaking personality who accomplished so much for those affected by the disease, but also interweaves and captures something of the personalities and stories of Betty and Harry Martin, even pointing in the direction of the intriguing Guy Faget, who introduced promin in Carville in 1941. Similarly, the chapter ‘Veterans of the Spanish-American War, II’ gives us the history of the irascible John Ruskin Early, managing both to capture the pathos, raw frustration, and utter madness of the man, as well as something of the spirit of Dr Isadore Dyer, William Danner, and the tortured legislative process that eventually led to Carville becoming the US National Leprosarium. Then the chapter on Paul Brand and Stanley Browne, which tells of two extraordinarily clear sighted and energetic workers in the medical field both in India and Africa, respectively, as well as internationally, also manages to include something of the parallel story of Michel Lechat. (It is extremely telling that Lechat is pictured here, not only with Graham Greene, but also with one of his children. The story of heroic contribution to leprosy conceals another story, as yet untold, and that is the story of the families of those who worked in the field – the story of the children of Robert Cochrane, Paul Brand, Stanley Browne and others.)

Gould has made excellent use of some of the now difficult to obtain, but classic, works that form part of the canon of narratives of leprosy. He has fleshed these out with his own finely judged primary research and pertinent interviews (notably with Eileen Lodge, Michel Lechat, Hugh Cross and Diana...
Lockwood). Hansen’s *Memoirs and Reflections* (Germany, 1979), Kate Marsden’s *On Sledge and Horseback to Outcast Siberian Lepers* (London, 1883), Perry Burgess’s *Who Walk Alone* (NY, 1940), Stanley Stein’s *Alone No Longer* (Carville, 1974), Betty Martin’s *Miracle at Carville* (NY, 1950) and *No One Must Ever Know* (NY, 1959); Peter Greave’s *The Second Miracle* (NY, 1955), *Young Man in the Sun* (London, 1958), *The Painted Leopard* (London, 1960) and *The Seventh Gate* (London, 1978), Phyllis Thompson’s *Mister Leprosy* (1980–1), and Brand and Yancey’s *Pain: the Gift Nobody Wants* (London, 1994) are a few of the classic pioneering accounts to which Gould has given new life by retelling them afresh within a moving but unsentimental overarching narrative of the continuing story of the battle against this disease. In addition, he has drawn on some early excellent research that could also have been forgotten. For example, his first chapter draws successfully on Laurie Stanley Blackwell’s extensively researched doctoral thesis and subsequent publications on the subject of the Arcadians with leprosy. This is supplemented with Philip Kalisch’s 1973 research and M J Losier’s *Children of Lazarus*.

Thankfully, this is not the last word on the subject of the history of leprosy. It simply opens the door to the possibility of so much more that can be profitably investigated. While leprosy research in the twentieth century has, for the most part, grown out of scientific rigor and cautious skepticism, leprosy history has been in danger of resorting to unexamined orthodox narratives. Many of these individual stories of the history of leprosy need to be placed more strongly within their social, political and economic contexts. Why for example was there such an emphasis on leprosy in Norway in the mid-1800s? Why not Estonia, where leprosy was endemic at much the same time? How is this emphasis connected to Norway’s desire to be an independent nation? To what extent does the American interest in leprosy in Hawaii and the Philippines have to do with its interest in them as colonies and as such suppliers of goods to US markets? For that matter, how is the discovery of leprosy in a particular country connected to that country’s need to demonstrate its modernity and gain international respect? Everyone is familiar with leprosy politics, but how often do we see how the work done against leprosy, including research, has been determined in unexpected ways by other seemingly unconnected political and economic priorities?

There is space for more work on the extraordinary influence of the Leprosy Mission and other NGOs in contributing to medical research and the international efforts against leprosy. The roots of the Mission to Lepers and its connection to the tradition of subscription for infirmaries and dispensaries that was operative in Ireland in the nineteenth century has not been sufficiently nor carefully enough examined.

There is also room for further research on different models of isolation and confinement, especially with a focus on the influence of Culion, Molokai, and Carville. We need to have a stronger and more detailed idea of the differences in approaches to isolation in countries such as Brazil, India, and Africa. Gould mentions the leprosy villages or settlements in Nigeria and the agricultural colony at Kolhapur in Maharashtra referred to in A. T. W. Simeons’s *The Mask of a Lion* (London, 1952), but this model was more extensive than is commonly realized.

Gould has done a wonderful job of representing the spirit of those affected by the disease at every stage of his book. Often, he has managed empathetically to provide insight into the points of view of those at the other end of the scalpel such as Kari Nielsdatter (whose eye Hansen attempted to inoculate with the bacillus) and Kaoru Matsumoto (who describes the outrage and humiliation of vasectomy in Japan).

Other times, in the voice of Waiahi who played croquet with Robert Louis Stevenson in Kalaupapa, or Dayamony, the Christian convert in Purulia writing to her sponsor in Scotland, he captures the incredulity that anyone would be bothered with them of those who have so thoroughly internalized the status that society has accorded them. He also captures the dilemma of someone like Chandra, caught in a dilemma of divided loyalties and responsibilities in Mary Reed’s Chandag. Most memorably though is the cry of victory of Tamiichi Tanaka in Japan at the success of the claim for compensation and justice.

This book makes an extremely worthwhile contribution to the history of leprosy. It is a great pity that the publishers did not have copies at the African Conference in Johannesburg, early last year. Many would have appreciated the opportunity to purchase it.

Jo Robertson