

# Introduction

Leprosy is a gravely misunderstood disease. . . . Even today clinical knowledge of leprosy runs far ahead of social acceptance and individual understanding. For the vast majority the terms leper and leprosy still produce images of people living apart from society, in . . . colonies, where blindness and deformity are rampant and where approach to the outside world is announced with the cry of unclean, unclean.

Hudson and Genesse (1982, 997)

Leprosy is an infectious disease of humans that is caused by *Mycobacterium leprae*, a slow-growing bacterium that is hard to contract, and the more recently discovered *Mycobacterium lepromatosis*. The type of leprosy a person has depends on the strength of their immune system. A high resistance to the bacterium leads to tuberculoid leprosy and a low resistance to lepromatous leprosy. Leprosy is curable and therefore should be a disease of the past. However, it is still little understood by most people, even in the information age. This may explain why it remains a stigmatized infection. Thankfully, in recent years, scholars have been evaluating how the history of leprosy has led to misunderstanding, sensationalism, and misrepresentation. Leprosy remains an infection surrounded by myths that have developed over the hundreds and even thousands of years it has been present in the world. It is viewed as declining in frequency today, although it is still present in many communities around the world. Leprosy can be considered a “special” disease in clinical medicine because of the socioeconomic consequences related to its propensity to disfigure, generate stigma, and severely affect the lives of people who have it.

## A NEGLECTED DISEASE

People often think that leprosy is not a major concern today, unlike malaria, HIV, and other infectious diseases. However, along with sixteen other diseases, leprosy is classed as a neglected tropical disease. In May 2013, the

World Health Assembly adopted a resolution about this group of diseases that urged member states to

- ensure country ownership of prevention, control, elimination and eradication programs;
- expand and implement interventions and advocate for predictable, long-term international financing for activities related to control and capacity strengthening;
- integrate control programs into primary health-care services and existing programs;
- ensure optimal program management and implementation;
- achieve and maintain universal access to interventions and reach the targets of the roadmap.<sup>1</sup>

To a large extent, this resolution is being adopted around the world. However, it has proved difficult to raise the funds needed to fully manage leprosy and its consequences for the people who have it; fund-raising for other infectious diseases such as malaria and HIV is much easier. Leprosy is also less frequently portrayed in the media and is the focus of less research compared to other diseases. As I was writing this book, the monthly feeds from the PubMed website often showed that six times more papers were published on tuberculosis, another mycobacterial disease, than on leprosy. This is probably largely because leprosy is seen as a declining disease. Tuberculosis, in contrast, is seen as a reemerging disease, one of the many we see in the third epidemiological transition we find ourselves in, when infectious diseases are becoming more resistant to antibiotic treatment. Other researchers have documented this decline in research on leprosy (e.g., Cairns Smith 1996). Schoonbaert and Demedts (2008), who also relied on the PubMed database, found that although 19,201 articles were published on leprosy over the period 1950 to 2007, the number of papers published each year peaked in the 1950s. As might be expected, a large proportion of these were written by authors in places where leprosy remained a challenge. Four journals, the *International Journal of Leprosy*, *Leprosy Review*, *Indian Journal of Leprosy*, and *Leprosy in India* published over a third of the studies Schoonbaert and Demedts identified.

Leprosy has often attracted attention in academia from medical historians and bioarchaeologists. The former group usually works with descriptions and depictions of leprosy in texts and artwork while the latter group documents evidence for leprosy in archaeological human remains (see chapters 5 and 6 of this volume). Medical historians tend to focus on

evidence in particular countries or during specific periods of time or on certain aspects of the history of leprosy, such as diagnosis and treatment. In bioarchaeology, most work has been on individual skeletons that have revealed evidence of leprosy from archaeological sites in a specific place and time period. Some have also written about the diagnostic criteria used to recognize leprosy in human remains and about the social aspects of people's experience of having leprosy in the past.

### GOALS OF THE BOOK

Published work on leprosy is quite fragmented. The main purpose of this book is to synthesize knowledge about it from a variety of disciplines. In this book, I consider past knowledge of leprosy in light of current understandings. My primary goal is to critically evaluate what we know today in order to better understand the experience of people with leprosy in the past. As I was doing the research for this book, it became clear to me that many people had a limited understanding of leprosy. Thus, a second goal of the book is to dispel myths about leprosy. Finally, I hope that the contents of this book will better inform the wider public about this infection and ultimately help those who have leprosy have better and more fulfilling lives than many do today.

A good starting point for a book about leprosy is a list of the myths about the disease. Unfortunately, many people accept these as facts and they have become ingrained in societies around the world. I found the following ideas to be the most prevalent among beliefs about the disease:

Leprosy is easy to contract.

Leprosy can be passed from one person to another rapidly.

Leprosy can be transmitted via sexual intercourse or by touching.

Leprosy can be inherited.

Leprosy cannot be cured.

Leprosy is described in the Bible.

When a person has leprosy, the fingers and toes “drop off.”

Leprosy is a tropical disease.

Leprosy is not a problem for people today.

In the past, all people with leprosy were segregated from society.

The chapters that follow will explore these statements in the context of recent knowledge and understandings. As a starting point, and as there did not appear to have been much research done on knowledge of leprosy in

the West, where the frequency of the disease is low, I conducted a survey of people in parts of the English population to assess their knowledge of leprosy. I collected data relating to these myths with a questionnaire that 270 people completed in 2012 and 2013 (see Appendix 2). Most people who filled out the questionnaire knew that leprosy is an infection, that it is most frequently seen in Asia, that it affects the nerves, and that it is curable. There were mixed understandings about what pathological organism causes the disease, how it is contracted, what the key predisposing factor was, whether fingers and toes “drop off,” and how people with leprosy were treated in the past. The overwhelming majority thought it was described in the Bible (nearly 80 percent), but see chapter 3. As Weymouth (1938, 22) said over eighty years ago, “Leprosy, to the average man, is merely a disease referred to in the Bible, and now, fortunately, no longer with us.” This belief is clearly still prevalent today, although leprosy is indeed still with us. The data I collected from this survey show that much work needs to be done to improve the general public’s knowledge of leprosy. Graciano-Machuca et al. (2013) made a similar point after conducting a survey of university students in India.

### THE WORD “LEPER”

In this book, I refrain from using the word “leper” except when referring directly to a quote from another source. When I do use it in my own writing, I put it in quotation marks to emphasize that I do not regard the word as useful or helpful for describing people with leprosy, past or present. Historian Luke Demaitre (2007, xii) also avoided this word: “The word *leper* has been shunned consistently—except when it is part of a modern quotation—and consciously because it amounts to a slur (in English notably more than in other Western languages).” In his book *Images of Leprosy*, Boeckl (2011, 7) avoided the word “except in quotations from scripture and other sources” (see also Brenner and Touati forthcoming). I learned from my questionnaire that most respondents associated the word “leper” with negative words and ideas. Definitions of “leper” provided in freely accessible online websites, the websites that people seeking information and definitions might visit, fit well with the data I collected with the questionnaires. This evidence shows that among the general public, not much has changed over the past few decades; Silla (1998, 10) also noted that people in the Western world view leprosy as a metaphor for “deformity and stigma or

a curiosity from the biblical/medieval past.” Further, it is often the case that authors of clinical papers talk more about the disease or the affected part of the body than about the person with the disease. A prime example of this is the article by Rohatgi et al. (2016); they titled it “The Story of a Deformed Leprous Foot.” Those who objectify a person with leprosy seem to suggest that the disease is a more important entity than the person’s identity (which of course includes characteristics beyond their infection). My hope is that others, especially those working in bioarchaeology, will also abandon the word “leper” in the future.

However, the signs are not good, as I noticed in September 2016 at a bioarchaeology conference. The word also continues to be used in clinical medicine (Grzybowski et al. 2016), in bioarchaeology (Magilton, Lee, and Boylston 2008; Roffey and Tucker 2012), in the media, and even on signposts (see Figure I.1). Indeed, an almost contradictory footnote appeared in a bioarchaeology paper regarding the word:

The term “leper” is employed throughout this article in the context of its traditional use in historical sources and previous scholarly works, and as a term peculiar to the Medieval and pre-modern periods. In this sense it refers to individuals affected, or perceived as having, leprosy (as applied to the anachronism “Hansen’s Disease”). It is acknowledged that the term has been used pejoratively in modern contexts and it is one of the aims of this article to challenge the root of such misconception. (Roffey and Tucker 2012, 170)



Figure I.1. Ripon “leper” chapel. Photo by Charlotte Roberts.