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Abstract: Age-old fears and misconceptions about leprosy have flourished for centuries and the condition remains both a socially stigmatizing issue and a public health problem in many parts of the globe. In the context of Islam, only a few personal narratives by Muslims living with leprosy exist, and no one has systematically reviewed accounts of leprosy related disability from early or recent Islamic history, including the Prophet Muhammad’s interactions with individuals living with leprosy. In this article, we present previously untold stories about leprosy, from both English and Arabic sources strongly rooted in Islamic values and principles. After an introduction and brief history of Islam, this article is divided into three main sections: (1) The foundations of early Islamic values about illness, leprosy, and disability; (2) Leprosy and stigma in Islamic communities and/or places; and (3) Art, storytelling, and other expressions by people living with leprosy in various parts of the world. The authors also discuss some of the challenges of defining leprosy terminology based on early historic documents. The overall purpose of this article is to describe historical and religious accounts of leprosy and amplify the collective voices and experiences of Muslims who live with leprosy from a disability studies frame. The authors also introduce the ‘House is Black’, a short documentary that illustrates additional insights and commentary related to disability related leprosy.

Keywords: Islam and leprosy related disability; stigma and acceptance; history; arts and storytelling

1. Introduction

“Allah (God) does not look at your outward form and your bodies but he looks at your heart and your deeds.”

This simple statement illustrates two fundamental and powerful points about Islamic values and the experience of living with a disease that, like leprosy, can be both disfiguring and disabling: disability is neither a divine curse nor punishment, and those more able and privileged have a duty to empathize with and support those who are disabled. The passage also offers an ideal launching point for exploring the role that Islamic values have played in the lives of Muslims with leprosy as seen through the lens of history, place, art and, perhaps most importantly, society.

1 Allah’ is the Arabic word for the One Allah, the Creator and Sustainer of the universe, and is widely used by Muslims (including many whose native language is not Arabic), as well as by Arabic-speaking Jews and Christians. The word is etymologically related to the Hebrew ‘Elohim’ and Aramaic ‘Alah’.
2 Hadith compilation of Muslim, vide Laher (2017) at the Summer Institute on Theology and Disability in Azusa, CA.
To date, little attention has been given to leprosy in the context of Islamic perspectives and disability studies and, as a result, the collection of published academic studies and narratives are limited [1]. Even apart from the paucity of literature examining the relationships between disability/leprosy and Islam, anecdotes about Muslims living with leprosy or other disabilities have rarely been explored in both disability studies and/or Islamic studies. We find this oversight to be problematic, not only from a human rights perspective but also from a practical one. Muslims comprise the majority religious and/or cultural population in 49 countries of the world, and among them, many have disabilities [2].

What is more, even a cursory review of the literature reveals that leprosy and its related social and ethical questions have long been part of Islamic culture and traditions.

In this article, we focus on the history and traditions, past and present, of how Muslims experience living with leprosy and its related disabilities, and how their experiences have varied depending on whether they lived in the general community, asylums, colonies, or other settlements. By drawing on English and Arabic sources, sacred scripts, historical texts, passages, and stories, we hope to produce a fuller and more descriptive analysis of the experience of leprosy and its wide-ranging effects among Muslims than previous studies. We begin by briefly introducing Islam and its values in the context of Muslims living with leprosy and/or related disabilities.

Challenges in the Historical Study of Leprosy

It should be noted that there are some well-known challenges in the study of the history of leprosy in general (including its study in the Islamic world and religious tradition) regarding the definition and meaning of leprosy [3,4]. In early Islamic literature, leprosy is not defined by a single term, and even with regard to the same subject, multiple terms are often used [3]. For example, ostensibly incompatible traditions and stories on the treatment of people living with leprosy can be found within the Islamic hadiths and the biographical literature (discussed in the next section) [3]. In general, the terms to describe leprosy have varied throughout different areas of the world and at different times.

With regard to Islam and leprosy, several different terms have been used to describe leprosy in the Quran and hadiths [3]. For example, the term baras is the only term used in the Quran to refer to leprosy [3]. The other most commonly used term to describe leprosy is judham, which can be found in the hadith and sira literature [3]. Interestingly, the verbal form of judham (jadhma) means to “cut off or amputate” which is thought to be how leprosy became associated with the Arabic term [3]. For example, one Arabic dictionary notes that judham causes a “cracking” of the skin [3]. The term majdhum (from the same root) refers to a person who is afflicted with judham [3]. While the terms abras and judham may suggest two different forms of leprosy, it is difficult to apply the strict definitions for leprosy established by lexicographers, as many were written after the major hadith works and early histories of Muhammad [3]. Finally, it is also challenging to classify or distinguish baras and judham based on modern descriptions, in part because, today, leprosy has many subdivisions [3]. Nevertheless, many physicians today agree that two main forms of leprosy exist (Tuberculoid and Lepromatous) [3].

Some other considerations are worth keeping in mind. Whereas the modern connotation of ‘leprosy’ is Hansen’s disease, Near Eastern people in Late Antiquity and medieval times did not classify diseases in the same way. While some of the words they used have commonly been translated as ‘leprosy,’ numerous writers have pointed out that people at that time used those terms more broadly than just for referring to Hansen’s disease. Thus, the Jewish Encyclopedia [5] explains that in the ancient world, people referred to a number of skin diseases (including Hansen’s disease) as leprosy, and that translation into several languages has compounded the confusion. The twentieth-century Tunisian Quranic exegete and commentator, Tahir ibn ‘Ashur [6], similarly observes that the disease called leprosy by the ancient Hebrews and Arabs (in Aramaic, tsaraath) is not the same disease as today’s leprosy, even though the same name may be used for both.

This article has drawn on medieval Arabic sources for biographical information on people living with leprosy, and we should therefore explain the Arabic terms for leprosy further. The Arabic words baras and judham are often translated as leprosy. Lane’s lexicon translates the first as leuce (i.e., vitiligo)
and the latter as elephantiasis. John Hutchinson’s nineteenth-century medical work [7] describes three types of ‘leprosy’: white leprosy (leuce), anesthetic leprosy, and black leprosy (elephantiasis). Since the gecko is referred to in Arabic as samm abras, perhaps ancient Arabs believed a superstition (still common in some parts of the Middle East and Asia today3) that this reptile causes leprosy. Arab lexicographers explain baras as being a condition in which white patches appear on the skin, which is consistent with the skin discoloration that is a symptom of Hansen’s disease, and a less-common term bahaq can refer to pale or dark patches on the skin. Judham on the other hand is explained, in medieval Arabic lexicons, as truncation of the fingers and toes (which matches another symptom of Hansen’s disease: the shortening of fingers and toes due to reabsorption) or falling off of the digits (a description that is may be based on a common misconception about the effects of Hansen’s disease, or is simply including some other ailment under the label judham due to an outward similarity in symptoms).

Persian Muslim physician ‘Ali ibn Sahl Rabbani (d. 850 CE) described the symptoms of judham as: falling out of the eyebrows, shrinkage (inkimash) of the nails, thinning (dumur) of the nose, and disfigurement (tashawwul) of the fingers and toes. The renowned Ibn Sina (Avicenna, d. 1037 CE), in his Canon of Medicine (which remained a medical authority in Europe until the eighteenth century), described judham as causing physical disfigurement and potentially ulceration, gangrene and falling off of limbs. Andalusian physicians appear to have been the first, in the Muslim world, to draw attention to numbness as a consequence of judham [8–10]. It appears that even though the terms baras and judham were originally used with broad scope in Arabic (in a way that encompassed Hansen’s disease as well as other ailments), Arabic-speaking physicians did come to use the term judham in particular to describe what are uniquely symptoms of Hansen’s disease, and it appears that European medicine drew heavily on these descriptions until the seventeenth century [10].

Notwithstanding this, we should also realize that the medieval Arab and Muslim historians and biographers may not have been privy to these insights. This, along with the terminological problem discussed above, leads us to conclude that it is probably difficult to make modern diagnoses from the rather limited descriptions we find in the hadith and biographical sources. However, given that the people at that time dealt with victims of all these skin ailments (including Hansen’s disease) in the same way, there is still value in citing these examples. Even if some of the individuals described as having lived from judham or baras were to turn out not to have had Hansen’s disease, they would almost certainly have faced a similar reception to Hansen’s disease patients in their societies.

2. A Brief Introduction to Islam

Islam is a religion that currently has about 1.5 billion followers worldwide. “Islam” means “submission” in Arabic and is etymologically related to the Aramaic and Hebrew root terms, and to the Arabic word salam [peace]. Thus, inherent to its name, Islam teaches its followers to seek peace through submission to Allah (God), the Creator of the universe. Islam is a scriptural religion, grounded in the Quran, a sacred text that Muslims believe was sent from Allah to Muhammad (d. 632 CE) in the form of a series of revelations. According to Islam, the Prophet Muhammad is the last in a line of prophets.

2.1. The Holy Book of Islam

The Quran’s central messages concern the core values of monotheism, human accountability, and judgment by Allah after death. It also contains a framework of moral teachings (mostly general concepts and guidelines, but also some specific rules or laws). The following two verses capture these central themes, referring not only to Islamic conceptions of morality and disability, but also accountability and its associated rewards and punishments.

"Indeed, Allah orders justice and kindness (to others), and giving (especially) to relatives, and forbids immorality and bad conduct and oppression. He admonishes you that perhaps you will be reminded."\(^4\)

"There is not upon the blind any guilt or upon the lame any guilt or upon the ill any guilt. And whoever obeys Allah and His messenger—He will admit him to gardens beneath which rivers flow: but whoever turns away—He will punish him with painful punishment."\(^5\)

Islam’s most holy book contains stories that specifically mention disabilities. Its description of the Israelite Prophet Moses—a revered figure in Islam—as having lived with a speech impediment\(^6\) conveys a powerful message about acceptance, respect, and integration of disabled persons. The Quran also tells how the infant Moses was set adrift on the Nile by his mother, to protect him from the death sentence pronounced on all Israelite baby boys by Pharaoh, only to be picked out of the river by the household of Pharaoh himself\(^7\). According to some Quranic commentators, the member of Pharaoh’s family who initially found the baby was Pharaoh’s daughter, who lived with leprosy (barsa’), and had been advised by physicians to bathe in the Nile for therapeutic purposes\(^8\). It is said that upon opening the basket and seeing the baby Moses, she was miraculously cured of her leprosy, as a result of which she declared he was a blessed child, and successfully pleaded with her father for his life\(^9\).

Among the miracles the Quran affirms for Jesus (another revered prophet of Allah in Islam) is healing, by Allah’s permission, those who are living with leprosy\(^10\).

2.2. Hadiths

The second primary source of Islamic religious teaching, the hadiths, are compilations by the Prophet Muhammad’s contemporaries of his sayings and actions. Their scope broadens the text of the Quran by expounding on theological, legal, ritual, and ethical matters. In contrast to the Quran, which is contained in a single book, the basic text of which has not been significantly disputed among Muslims, the hadiths are a more diffuse body of literature. The reliability of specific hadiths is sometimes contested among Muslim scholars, who devised a critical framework for evaluating hadith reliability based on a detailed study of its transmission history and its content. Hadiths are therefore graded by Muslim scholars as either sound (sahih, which implies that one can be confident—even if not totally certain—that the Prophet Muhammad actually said it) or dubious (da’if, which implies that it is unlikely that the Prophet Muhammad actually said it).

Numerous sound hadiths deal with disabilities, including leprosy. Echoing Jesus, Prophet Muhammad encouraged people to help the disadvantaged by saying, “Seek me among your weak.” He gave time to the disabled, such as the mentally disabled woman who poured out her concerns to him, and he facilitated the integration of disabled individuals into society (e.g., by appointing a blind man, Ibn Umm Maktum, to a prominent position of authority).

Numerous sources portray Muslim leaders living with some kind of disability while also enjoying prominent social status and holding important positions. The examples chosen for this article are derived from Quran and the hadiths as well as historical and contemporary perspectives \(^13\). One prominent example is Ata’ ibn Abi Rabah (647-732 CE)—black, physically disabled, and

\(4\) Quran, 16:90.
\(5\) Quran, 48:17.
\(6\) Quran, 20:25, 26:13, 43:52.
\(7\) Quran, 28:7–8.
\(8\) Therapeutic bathing for those living with leprosy has been widely practiced, across history and cultures \(^8\).
\(10\) Quran, 3:49, 5:110.
paralyzed—yet acknowledged by history as the greatest Mufti (a legal expert who is empowered to
give rulings on religious matters) during his time in Mecca, the holiest city in Islam.

This article presents an Islamic perspective on leprosy and leprosy related (or other) disabilities,
as well as information about the social, cultural, and economic status of Muslims living with leprosy
in Muslim-dominant countries, and the attitudes of Muslims toward community members living
with leprosy. Previously published studies that we consulted in this emerging area of scholarship
include Vardit Rispler-Chaim’s *Disability in Islamic Law* (2007); Mohammed Ghaly’s *Islam and Disability:
Perspectives in Theology and Jurisprudence* (2010); and Kristina L. Richardson’s *Difference and Disability in
the Medieval Islamic World: Blighted Bodies* (2012).

Our article is divided into three parts. In Part 1, we begin with the foundational and historical
values of Islam as they apply to leprosy and other illness or related disabilities. Part 2 provides an
overview of why leprosy is unique among medical disorders in how it can cause disability, social
stigmatization, and segregation. We also explore the intersectionality of Islam, disability related
leprosy, stigma, and place (i.e., family/community/country and leprosy colonies). In part 3, we look
at the role that prominent Muslims have played in the military and arts including films, poetry, and
storytelling in the context of leprosy and Islam. Our primary example is the Iranian film, *The House is
Black* (1962), which takes an unusual approach to depicting a leprosy colony in a Muslim-dominant
country. This article concludes with suggestions about how future disability studies and Islamic
studies scholars can explore the status and well-being of Muslims living with leprosy. In addition,
we conclude this article with a summary and recommendations.

2.2.1. Part 1: Foundations: Early Islamic Values about Illness, Leprosy, and Disability

Although the exact origin of leprosy is poorly understood, a combination of three methodologies
has provided insights into its origins and spread throughout the world: comparative genomics
(which compares DNA sequences among different organisms for clues to their geographic origins
and evolution), classical paleopathogy (which studies ancient diseases based on evidence from fossils,
skeletons, and other remains), and ancient writings. Regarding the first approach, recent comparative
genomic studies suggest that the main causative bacterium, *Mycobacterium leprae*, evolved in either
East Africa or South Asia during the Late Pleistocene (which ended about 11,700 years ago) [14,15].
From there, leprosy spread through successive migrations to Europe and the rest of the world [14].
Some researchers hypothesize that if *M. leprae* evolved in Africa, the disease may have migrated
to India around the third millennium BC, when there was substantial interaction among the Indus
civilization, Mesopotamia, and Egypt [14]. Potentially supporting this view, a recent genetic analysis
of *M. leprae* estimated that the most common recent ancestor of the microorganism dates to 2543 BC
to AD 36. As for paleopathological evidence, the oldest documented skeletal evidence suggests that
the lepromatous form of leprosy was present in India by 2000 BC [14,15]. Finally, the earliest widely
accepted written record of leprosy is from Asian texts dating to 600 BC [14,15]. Despite the intriguing
clues gathered from all three methodologies, it should be kept in mind that the origin of leprosy is an
active area of research and that the final word has not yet been written.

Based on the above genomic and archaeological evidence, leprosy had been well known throughout
India and the Middle East for millennia when the Prophet Muhammad, at the age of 40, began to
receive the revelations that led to the development of Islam in 610 CE [3]. According to tradition, Islam
was born when Prophet Muhammad received a series of revelations from the Angel Gabriel in a cave
in Mecca, in what is now western Saudi Arabia. These revelations were transcribed into the Quran, the
holiest text in Islam. The Quran was quickly followed by the transcription of hadiths, observations by
the Prophet’s contemporaries about his words and actions. Over the ensuing centuries, the followers of
Prophet Muhammad would spread Islam throughout the Arabian Peninsula and the rest of the world.
Leprosy in the Time of the Prophet Muhammad

One of the first critical questions about Islam and leprosy is simply: did the Prophet Muhammad ever meet people with leprosy and, if so, what were his views about interacting with them?

While, as we noted, the Quran briefly mentions Prophet Jesus and his interactions with people with leprosy, and extra-Quranic exegetical sources mention the influence of leprosy in the early life of Prophet Moses [3], there are no specific references in the Quran to the Prophet Muhammad interacting with individuals with leprosy. Nevertheless, several lines of evidence—some of it ostensibly contradictory—strongly suggest that such interactions did in fact occur.

Stories and Contradictions

Three well-known hadiths refer to Prophet Muhammad’s interactions and advice regarding individuals with leprosy [13]. These hadiths, interpretations of which are central to the theological dimension of the issue at hand, have strongly influenced the social, medical, and legal views of leprosy throughout the Islamic world for centuries [16].

In the first hadith (generally regarded as sound, although not unanimously accepted), Prophet Muhammad reportedly said: “Escape from the leper as you escape from the lion.”[11]

A second sound hadith relates that an individual with leprosy came to the mosque one day to swear his loyalty to Islam. According to this account, Prophet Muhammad asked him to keep his distance, though he did accept the man’s allegiance[12]. Another similar hadith (graded as dubious) seems to be warning healthy people to “keep away the distance of one or two spear-lengths from those with leprosy.”[13]

In a third hadith (graded as sound), it is said that Prophet Muhammad asked an individual with leprosy to join him for a meal and actually took the man’s hand and put it in a dish[14], telling him, “Eat, in the name of Allah, trusting in Allah and putting your reliance in Him.”[15]

Over the centuries, the three hadiths[16] reproduced above have been extensively discussed and debated by Muslim scholars[17]. To resolve the apparent contradictions among them, it is important to

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11 The narration can be found in the hadith compilation of Ahmad, and also in the canonical compilation of Bukhari; see ‘Asqalani [17] (vol. 10, p. 158).
12 The narration can be found in the canonical hadith compilation of Muslim; see ‘Asqalani [17] (vol. 10, p. 158).
13 The narration can be found in the hadith compilation of Abu Nu’aym, but was not considered to be credible by Muslim hadith scholars; vide ‘Asqalani [17] (vol. 10, p. 159).
14 Recall that it was a norm in the pre-modern Middle East, and remains so in some communities, for people eating together to eat from a single large dish, not from individual plates.
15 The narration can be found in the hadith compilations of Abu Dawud, Tirmidhi, Ibn Hibban; vide [17–19].
16 There is a fourth hadith that mentions leprosy, but is of only tangential relevance here, as it does not say anything about interactions with people living with leprosy. Many Muslim scholars grade it as being of dubious reliability. It says that if someone hoards foodstuffs, then God will smite them with leprosy (judham) and penury [17] (vol. 4, p. 348). It is strange that Dols [16] has taken this hadith to indicate that “leprosy is often invoked as a curse on those guilty of immoral behavior.” At most, if the hadith in question is taken as reliable, it would indicate (as some passages in the Hebrew Bible do) that leprosy might sometimes be used by God to punish certain people. As Jahiz has indicated [16,20], the source of the notion of leprosy as invariably being divine punishment might well have come from outside the Islamic world.
17 See discussions by ‘Asqalani [17] (vol. 10, pp. 158 ff), ‘Uthmani [21] (vol. 4, pp. 333–341); vide [16]. The advice to run from the leper raises an important issue. Scientifically, it appears problematic because leprosy has been proven to be much less contagious than it has been assumed to be over the course of human history. Thus, one possible approach for Muslims would be to contextualize the hadith, something for which there is long-standing precedent in Islamic theology and jurisprudence. Thus, they would assume Muhammad gave the advice based not on the authority of Allah but on the medical assumptions of his time. In this case, his words would not be religiously binding. Such a conclusion would enjoy longstanding hermeneutic precedent in Islamic jurisprudence. On the ethical front, even medieval commentators of the hadith realized that running in panic from a leper is likely to be offensive to the leper himself, and thus appears to be in contradiction with the general ethical principles of Islam, not to mention that it also contradicts the Prophet’s own close interaction with lepers, and his advice (in another hadith) not to stare at a leper. It is also worth observing that even some pre-modern Muslim authorities have expressed doubt as to the reliability of this narration. The Prophet’s wife Aisha, when asked about the above hadiths, denied that the Prophet ever said to run from a leper, adding that she herself ate from the same dishes and used the same sheets as one of her own servants who had leprosy. According to the fourteenth-century historian and jurist Shams al-Din al-Dhahabi, “That person who eats with a leper, trusting in Allah and putting reliance in Him, is the [true] believer.” [22] (vol. 2, p. 143). Another possibility here is that the leprosy the Prophet referred to was
understand how Islam and its followers viewed the nature of disease or disability compared to their Jewish cousins in the Middle East and their Christians contemporaries in Europe during medieval times. Christianity inherited from Judaism the belief that the human body and soul are inseparable during earthly life. The Hebrew Bible mentions incidents in which specific sinners are punished by being afflicted with leprosy, though the Bible does not state that all cases of leprosy result from sin. According to Dols and Zamparoni [16,23], in medieval Europe, the conviction that leprosy was a sign of divine punishment—and unequivocal indication of the presence of sin and evil—was clearly the dominant Christian belief at the time.

In addition to leprosy being attributed to various moral sins from the eleventh through fourteenth centuries, it was also used as a means for social and political control of those living with it [24,25]. In contrast, the Islamic view is closer to the modern views held by Judaism—namely, that all events, including disease, are caused by the Divine Will alone, for reasons not always known, and therefore are not necessarily expressions of punishment [13].

The Quran explicitly states that the blind, lame, and sick bear no fault or blame for their conditions [16]. Although the exhortations to withhold blame from ill people (from Quran) while also (according to these three hadiths) physically avoid contact with them appear to be contradictory, they simply indicate that Muslims believe that all diseases are caused by the will of Allah and also recognize that diseases can be contracted by close contact with those afflicted. Mohamed [13] notes that the first two hadiths reflect Prophet Muhammad’s awareness that leprosy can indeed be transmitted by close contact—probably based on actual experience—and that the third hadith illustrates his belief and confidence in the will of Allah (i.e., that he would not necessarily contract leprosy through close contact unless Allah willed it, and that contagion is not an autonomous force independent of God). In modern times, a near-consensus has emerged on this view, which blends spiritual and epidemiological data and insights.

Leprosy and Muslims in Leadership Roles

The acceptance of people with leprosy in early Islam is seen in cases where individuals known to have the disease played important leadership roles. For example, one prominent early Muslim with leprosy (judham) was Mu’ayqib, from the tribe of Daws. Like many early converts, Mu’ayqib was persecuted for his faith until he managed to escape from Makka (Mecca) and (along with a number of fellow believers) emigrate to Abyssinia. Later, when the Muslims had established a safe haven and community in Medina, Mu’ayqib returned. Prophet Muhammad then appointed him custodian of his official seal, a responsibility that he continued even after the Prophet’s death.

The three subsequent leaders of the Muslim community—the Caliphs Abu Bakr, ‘Umar, and ‘Uthman—subsequently appointed Mu’ayqib to official positions of financial administration. In fact, ‘Umar reportedly (in emulation of the Prophet’s example) sat and ate with Mu’ayqib from the same plate. ‘Umar was also intent on seeking treatment for Mu’ayqib and eventually found two medical

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Historically and in modern times, Muslims have largely had a healthy attitude toward science. Educating the general Muslim public on the scientific aspects of leprosy as well as the jurisprudential and exegetical nuances and ambiguities surrounding the hadith texts in this matter could go a long way to eliminate stigmatization arising from simplistic and superficial conclusions that laymen might draw from hadiths.
practitioners who, through a treatment with colocynth (a bitter desert fruit), managed to halt the progression of his disease [22].

Early Modern Treatments of Disease, Leprosy, and Disability

Between Europe and the Middle East, the differences between early modern Christian and Islamic views of disease/disability in general, and leprosy in particular, produced vastly different places and policies to care for those with leprosy. For example, while both types of societies created leprosaria and colonies for people with leprosy, the underlying motives were often very different. According to Dols, the leper house was ubiquitous throughout medieval Europe as a refuge for the despised, probably as a result of the Christianization of Europe, which took seriously the biblical warnings about how to treat people with disfiguring skin diseases [16]. The fact that Islamic society did not judge people with leprosy in a similarly harsh way may be explained by its strong Galenic (i.e., early medical) interpretation of disease and less stringent religious condemnation [16]. For example, in the Middle East, numerous historical documents and accounts indicate that Islamic treatment of patients with leprosy was both humane and scientific, as seen with the emergence of the first Islamic hospital, or bimaristan (from the Persian bīnār, sick and -istān, place) [27,28].

Bimaristan

Arab historians have traditionally considered ‘Umayyad Caliph al-Walid to have established the first Muslim bimaristan in Damascus in AD 707 [16,27]. The historian al-Tabari (d. 923 CE), drawing on his own earlier sources, reported that “al-Walid confined the lepers so that they would not go out among the people, but added that, “He ordered that provisions be provided to them, and this was done.” [27,29]. An analysis of the historical evidence strongly suggests that the bimaristan—which has been described as differing from leprosaria or sites supporting the blind and disabled because of its highly medicalized approach and focus on helping patients [30]—only emerged later, in Abbasid times [30,31]. Nevertheless, al-Walid probably did set up a leprosarium in the sense of “a small facility that provided services to the crippled, blind, and lepers” [27,30].

It was probably not until in the late eighth century that a new type of medical-cum-charitable institution—the bimaristan—emerged, as a “hybrid of the [earlier] politico-charitable institutions of the Eastern Mediterranean” [30]. Some scholars [27,30] theorize that credit for the first Islamic bimaristan should possibly go to the Abbasid vizier Yahyā ibn Khalid ibn Barmak (d. 806 CE), who was known for his generosity, his buildings, and his support of Persian culture [27]. Dols speculates that Yahyā may have created the first bimaristan in Baghdad sometime before 803 CE [27]. In any case, bimaristans became known for their patronage, large size, generous funding, and for being exclusively medical institutions [27]. Interestingly, unlike the Byzantine hospitals that may have served as a prototype, Islamic hospitals were not run by the religious establishment, but a high-placed government official [27]. In addition, although the bimaristan was influenced by the humane Christian practice of caring for the mentally ill, it replaced Christian supernatural healing with Galen’s humoral pathology [27].

In subsequent years, the influence of bimaristans and the practice of separating people with leprosy, due in part to concerns about its contagiousness, was seen in other areas of the world. For example, the first Muslim hospital in North Africa appears to have been built around 830 CE [16]. It was located near a separate building called the dār al-judhamāt (house of the lepers), where people with leprosy were given medical attention [16]. According to the Islamic scholar and traveler Leo Africanus (1485–1554), in the early sixteenth century, about 200 houses were designated for people with leprosy in a suburban quarter outside of Fez, Morocco [16]. Africanus, who had been a secretary of the bimaristan for two years, also reported that these individuals received revenues from several endowed properties and were well provided for [16].

In the later Middle Ages, the Turks built numerous hospitals in Anatolia that followed the precedent of the Islamic bimaristan, including hospitals in Kaysari (1205 CE), Sival (1217 CE), and Kastamonu (1272 CE) [16]. One such leper house, built in Edirne, Turkey at the time of Murād II
(1421–1451), operated for nearly two centuries [16]. In addition, in 1530 CE, Sulayman the Magnificent built a leprosarium in Scutari that survived into modern times [16].

Finally, a leper house that was founded by Selim I in 1514 and that survived until 1920 is a good example of leprosaria or quarters located outside of cities [16]. This facility was described by Sûheyl Ünver in his book, About the History of the Leprosaries in Turkey, as follows [16]:

“The leprous were taken care of by the religious foundations []; 40 loaves of bread as well as soup and rice were sent to them each day from the foundations of ‘Atik Valide. Their wood for the winter as well as their garments were equally provided from this same foundation. Donations of money and sacrifices of sheep given by those passing through the city of Üskûdar on their way to Anatolia were also accepted… The patients lived in their rooms and could marry among themselves … [In 1934] there were, in an isolated building, 10 wooden rooms for the married and 6 rooms for the bachelors, each with a fireplace.”

2.2.2. Part 2: Cracks in the Foundation: Leprosy and Stigma in Islamic Communities

The effects of leprosy or leprosy related disabilities on people who contract it are uniquely devastating, varied, and widespread. Because the condition may cause physical deformities of the face and extremities, as well as physical disabilities involving sight and touch, leprosy affects people’s physical, psychological, social, and economic well-being. For centuries, from a clinical and sociological perspective, leprosy has been considered one of the highly visible dermatologic conditions, as people living with leprosy around the world have routinely faced isolation, exclusion, and stigma [23,32]. Some of the more disfiguring symptoms of the disease have often led to “horror and revulsion,” and “triggered irrational reactions that have proven difficult to overcome” [32].

Regardless of what time period or area of the world in which it occurs, leprosy exerts a remarkably similar impact on the lived experience of the condition; it may interfere with mobility, interpersonal relationships, marriage, employment, leisure activities, and participation in social and religious activities. These far-reaching social impacts are so severe that leprosy often causes people to avoid health care services. Lack of treatment, which often leads to a further deterioration of health, and socioeconomic status, also worsens social inequalities, which in turn are felt at all levels and places associated with the individual, family, institutions, and society [33].

Another effect of leprosy is often overlooked: although it has been technically “curable” since the development of multidrug therapy (MDT) in the 1970s, and despite the efforts of the World Health Organization since 2000 to reach global elimination, there were still more than 200,000 cases registered globally in 2018 [34,35]. Numerous studies indicate that the lack of “true” eradication can be attributed to social and cultural stigmas, which act as strong deterrents to elimination of the disease [33].

A Closer Look at the Role of Stigma

The social and cultural stigmas around leprosy may arise in part from the fact that it is essentially two conjoined diseases [36]: (1) epidermal manifestations that can cause patches of discolored skin, nodules, ulcers, and the loss of eyebrows or eyelashes; and (2) peripheral nerve damage that can cause paralysis, shortening of toes or fingers, nose disfigurement, and blindness [37]. Unfortunately, negative reactions from others are commonly triggered by any diseases that alter the color, complexion, texture, or appearance of human skin.

These negative reactions often lead to social isolation, seclusion, discrimination, and/or ostracization from the neighborhood or community [38]. The result is stigmatization, which has been defined as:

Treating an individual based on attributes that are viewed as so “deeply discrediting … [that] the stigmatized individual is not accepted and not accorded the respect, rights, and regard of his or her peers and is disqualified from full social acceptance … The individual is reduced from a whole and usual person to a tainted, discounted one”. [38]
As previously stated, leprosy has been part of the human condition since antiquity. The Muslim physician Avicenna (980 AD–1037 AD) called it a “universal disease” and “universal canker” and, as noted earlier, Europeans in the Middle Ages saw physical deformities as a sign of divine punishment and unequivocal indication of the presence of sin and evil [23]. According to Zamparoni [23], in some cases people with leprosy were suspected of poisoning wells and rivers, accused of plotting to take over towns and the countryside, and even triggered panic [23]. As a result, leprosy patients—perhaps as part of a broader movement to target all “deviants” who represented real or imagined threats—were sometimes severely persecuted, tortured, or burned alive in public squares [23]. Thus, perhaps it was a sign of humane treatment when the full segregation in the form of leprosaria, or lazars, began in Europe in the fourth century and in many places became the norm over the next 200 years [4].

Unfortunately, today the stigmatization of leprosy remains common in many parts of the world, where people with leprosy experience reactions that range from lack of sympathy to insults, societal rejection, and open hatred [4,39]. Not only are some forced to leave their communities, but their stigmatization often extends to their families as well [39]. One study found that families who had member with leprosy related disabilities were ten times more likely to experience social problems than those without deformities [39].

A quotation from Lusli [40] illustrates the isolation and frustration leprosy causes for individuals. A 15-year-old girl from the Cirebon District of Indonesia stated:

“My parents have always hidden my disease from me. I was eager to know, but no one wanted to tell me. Even my health worker [did not tell me]. I was angry at myself. People around me just asked me to take rest and stay in my bedroom.”

Stigmatization in the Islamic World

In Islamic communities, the impact of leprosy is most apparent in three key “places”: family, community, and government. That leprosy continues to be a problem in the Islamic world may come as a surprise to some, given the description in the previous section of historic Islamic attitudes and evidence of the respect with which people with leprosy and other disabilities have historically been treated. According to Mohamed, 1985 [13], leprostigma among Muslims tends to arise from complex indigenous traditional beliefs that predate Islam and are thus unrelated to normative Islamic teachings. He also observed that most of the wrong beliefs and practices observed in some Muslim communities regarding leprosy have no religious justification and affirmed that there is no religious basis in Islam for the concept of leprosy as a retribution for sin.

Leprosy in present-day Muslim communities has been documented and studied in a number of Islam-dominant countries, including Pakistan, Bangladesh, Indonesia, and Iran. Examples from each of these countries highlight how the complex and interrelated roles of place—family, community, and government—can affect those with leprosy and their families. For example, one study in Pakistan looked at the role of culture in treatment adherence among patients with leprosy [41]. The goal was to investigate why nearly one-third of the known 18,000 patients with leprosy had dropped out of their treatment programs. One key and disturbing finding revealed that of the 128 patients interviewed, more than half of those who did not comply with treatment denied even having leprosy.

Mull and colleagues attributed this denial to a coping mechanism brought about by the severe stigma associated with the disease. “The presence of close-knit extended families, in which joint decision-making was the norm and in which such a dread diagnosis could spell the end of job and marriage prospects even for distant relatives, contributed to the likelihood of denial” [41].

These researchers also found that many patients with leprosy initially consulted traditional healers, poorly trained physicians, and/or untrained medical practitioners, which led to lengthy delays before a correct diagnosis is made. Moreover, even after diagnosis, only 5 (4%) of the 128 patient sample attributed the cause of the disease to an infectious organism. This study did examine the roles of family and community in the lack of proper treatment of patients with leprosy; however, pervasive poverty
and illiteracy in Pakistan were also faulted. According to the researchers, “leprosy is most prevalent among the poorest of the poor” [41].

A more recent study in Bangladesh assessed how socioeconomic factors and stigma affected the quality of life (QOL) of 189 patients with leprosy [42]. Perceived stigma was found to have the highest association with adverse QOL in the sample, compared to the general population. Other factors that contributed to lower QOL for patients with leprosy included fewer years of education, the presence of deformities, and a lower annual income.

Although the role of government and official policies about people with leprosy may seem more conceptually abstract than everyday effects produced by families and communities, some researchers believe that the larger social, political, and economic environments created by government are also significant factors. Kazeem, 2011 [33] noted that governmental policies and laws about leprosy in some countries have lagged behind scientific breakthroughs. In India, for example, the pace of leprosy legislation has been slow. Kazeem also observed that in Japan, long after the development of MDT treatment, some governmental policies continued to encourage leprosy stigmatization and that violations of the human rights of people with leprosy included forced abortions, sterilizations, and isolation on remote islands.

Kazeem concluded that governments have generally avoided enacting legislation to support people; that even when laws are passed, implementation is often challenged by budget limits; and that this reluctance may be due to the misimpression that leprosy has been eliminated and therefore is no longer an important public health problem or a disability studies opportunity [33].

In any case, several key lessons have emerged from studies about leprosy caused by family, community, and government. For example, in the 1989 Pakistan study, Mull and colleagues concluded that their results emphasized the need for better training of physicians and other health care providers in the early diagnosis of leprosy, as well as better education for diagnosed patients. Effective leprosy treatment, they stated, “must include counseling of extended families and education of the public at large as well as enhanced communication with the patients” [41].

This observation was amplified by Kazeem [33], who noted that providing facts is not enough and does not lead to widespread stigma reduction. As these researchers observed, leprosy interventions must target individual, community, and policy levels:

At the community level, health education campaigns must shed light on leprosy through messages that sensitively deal with the local community’s beliefs and misconceptions while driving home the right information about leprosy to the people. The messages must be structured to make sense within the logic of people’s worldviews whilst they tackle leprosy stigma in broad contexts. [33]

2.2.3. Part 3: Recognizing Muslim Voices: Art and Other Expressions by People Living with Leprosy

Some of the examples presented in our article concern religious and spiritual leaders with leprosy or a family member with leprosy. This section is devoted to describing prominent Muslims who were leaders in areas such as the military, the arts, literature, music, and film making, and whose experience with leprosy has been significant in the context of their accomplishments.

In the case of military life, in the eighth century, the Umayyad dynasty was toppled in a revolution led by a man from Khorasan named Abu Muslim (d. 755 CE), whose flag-bearer, Abu Hammad al-Marwazi (a Persian from Merv), was living with leprosy (baras). One of the kings of the subsequent ‘Abbasid dynasty, al-Ma’mun (d. 833 CE), appointed a military commander named Ja’far al-Khayyat. Ja’far, who lived with leprosy (baras) and was renowned for his chivalry, eloquence, and famously long beard20.

20 These individuals are all mentioned in Jahiz’ book [20].
Poetry has been an important element of Islamic literature both as an artistic expression and a form of sacred writing. Two famous Muslim poets with leprosy in the Umayyad era (661–750 CE) were Mughira ibn `Amr al-Abras (d. 711 CE) and Shabib ibn al-Barsa (d. ca. 718 CE). Shabib’s mother and the mother of Khalid ibn al-Barsa (a companion of the Prophet) were both women with leprosy (al-barsa is Arabic for a female with leprosy). Among the courtiers of the Umayyad king Walid ibn Yazid (ruled from 743 to 744 CE) were three brothers living with leprosy who were all poets. Around the same time, a prominent rebel commander, the Kharijite Qatari ibn Fuja’a, is known to have had leprosy in his family (both he and his son lived with the condition).21

A renowned singer of the ‘Abbasid era, known as ‘Alluya (his actual name was ‘Ali ibn ‘Abd-Allah ibn Sayf, d. ca. 830 CE), also lived with leprosy (baras). ‘Alluya is said to have been unrivaled in artistic ability, proficient with the lute despite his left-handedness, a gifted singer, and an eloquent speaker and comedian. The leprous patches on his neck were largely hidden by his beard but would show during an animated performance. According to one account, he died when his servant mistakenly gave him a large quantity of opium in place of his leprosy medication. In another version, he died after taking medicine sent to him by a prominent physician, Yahya ibn Masawayh (d. 857 CE), who had been encouraging him to seek treatment.22

Muslim belletrist and polymath Abu ‘Uthman ‘Amr ibn Bahr (d. 868 CE), nicknamed al-Jahiz (the Bug Eyed), wrote a book [20] entitled Kitab al-Bursan wal-‘Urjan wal-‘Umyan wal-Hulan (The Book of the Lepers, the Lame, the Blind and the Squint-Eyed), in which he presented prominent individuals from Islamic history who had these and other disabilities. His aim was to show how disability did not impede these people from rising to the heights of achievement and fame, as well as how they struggled with, coped with, and even took pride in their disability [16].

Language and rhetoric are powerful tools in giving a voice to and promoting acceptance of those with leprosy. Jahiz [20] mentions that Bedouins once believed that leprosy enhances beauty. Indeed, perhaps it is not by coincidence that abras, the Arabic word for leper, is also a name for the moon.23 Mu’awiyah ibn Huzn, a pre-Islamic chief of the Arab tribe of Bani Rizam, was nicknamed “al-Muhajjal” (“the White-Socked Horse”) because his calves were afflicted with leprosy. He composed lines of poetry addressing his beloved (who was named May): “O May! Let it not repulse you that I’m lean, or that upon my legs whiteness prevails. For the swift and powerful steed’s distinction is not complete save with a white-socked gait!” The Umayyad poet Mughira ibn al-Abras also wrote lines of poetry expressing such sentiments.24

Leprosaria and “The House is Black”

Leprosaria have a long history in the Islamic world. Accounts from Islamic Spain in the ninth century [16] report that most towns had quarters for those living with leprosy outside city walls that were supported by pious foundations and were often close to aristocratic parks [16]. Dols [16] quoted a report from the 1500s that described a leprosarium founded in Istanbul by Selim I:

The leprous were taken care of by the religious foundation; 40 loaves of bread as well as soup and rice were sent to them each day . . . Their wood for winter as well as their garments were equally provided from this same foundation. Donations of money and sacrifices of sheep given by those passing through the city were also accepted . . . The patients lived in their rooms and could marry among themselves. [16]

According to Dols [16], although segregation has been a component in the treatment and everyday lives of people with leprosy in both early and current Islamic communities, especially compared to

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21 op. cit.
22 op. cit.
23 See Ibn Manzur’s lexicon [43] (entry on root b-r-s).
24 See again Jahiz [20].
other conditions or disabilities, individuals with leprosy have had remarkable freedom of movement even when they have resided in asylums, colonies, and settlements. In fact, many individuals (not just less-serious cases) have not entered leprosy communities at all, but instead have enjoyed active and busy lives and have received care in their homes and at other locations. Dols attributes this approach, which has probably been common in Islamic societies, to a strong sense of familial responsibility (a value that is promoted in Islamic teachings; see Quran 4:36 for example). In fact, Dols traces familial medical care in Islamic communities to antiquity, when bimaristans (as previously discussed) primarily served the poor.

An important artistic work at the nexus of disability, leprosy, and residential treatment has been supplied by the Muslim country of Iran. In her 1963 short, experimental documentary film, *The House Is Black*, Iranian filmmaker Forough Farrokhzad explored memories of leprosy in Iran and its contemporary impact. The film, funded by the Society for Assistance to Lepers, focuses on the Bababaghi Hospice—an actual colony of people and families living with leprosy—to spotlight the social neglect and isolation of people with leprosy in Iran. Though Farrokhzad was tasked with creating a documentary, she departed significantly from an objective rendering of the community by juxtaposing a poetic and journalistic approach. In the film’s voiceover, Farrokhzad narrates her own poetry and religious passages over visuals depicting life in the colony. These poetic elements jarringly co-exist with straightforward depictions of the colony’s hospital, as a male voice narrates the barest of factual information about leprosy itself. The film incorporates both still and moving images of leprosy patients of all ages, accompanied by melodious chanting of verses from the Torah and Quran.

Film scholars consider the piece to be an important precursor to the Iranian New Wave of the 1970s, an artistic movement “distinguished by its philosophical inclination, social critique, poetic disposition, and vigorous experimentation” [44,45]. This artistic approach, which combines pragmatic documentation, secular cinematic innovations, and religious perspectives, aligns well with the principles of Islam discussed in earlier sections of this article. Even though Farrokhzad herself did not see herself as a religious spokesperson throughout the film, members of the colony continue to pray and sing in praise of Allah and show no self-pity [46].

While scholars have discussed the film in relation to the Iranian New Wave, Iranian politics, and feminist poetics, it has yet to be discussed in the context of disability representations [47]. According to disability arts scholar Carrie Sandahl [44], part of what makes *The House Is Black* so unique from a Western perspective is that, despite its experimental formal elements, it focuses on disabled people living in a community [44]. In contrast, most documentaries made in the United States about the disability community focus on self-determination within a civil rights framework [48]. Unlike some Western filmmakers, Farrokhzad does not attempt to promote inclusion or mainstreaming. Nor does she, as a nondisabled observer, present her story through an inspirational, educational, or adversity based narrative. Rather, *The House Is Black* shows disabled people living in a segregated community, thereby revealing a world in which disabled people are interdependent and shown taking care of each other. We see that this community also includes children, some of whom appear to have leprosy and others of whom do not. Providing a broad and diverse perspective on this community, the film shows a full spectrum of emotions, embedded not in a culture based on exclusion, but rather in religious devotion, music, poetry, dance, festival and joy [42].

Sandahl [44] notes that, from a Western perspective, the film raises many questions. What is this community? Are they segregated by choice or by force? Who is the filmmaker? What is the relationship between the filmmaker and the subjects? How is disability understood in the context of this story? Are those within a leprosy community distinct from others with impairments? Does this representation (now more than 35 years old) reflect current conditions? What is the message, if any? And so on. Perhaps the ultimate artistic message and value in this type of cross-cultural exploration of disability is in the prompting of such questions in themselves. By intention, they force the viewer to abandon binary thinking between right and wrong, good and bad, positive and negative. They ask the
larger question: how does exploring disability from another cultural perspective offer models that disrupt binary viewpoints and suggest new ways of thinking and being?\footnote{Carrie Sandahl, Disability Studies Faculty and Disability Arts Scholar, 2017. Private email correspondence and interview [44].}

Sheibani [49] echoes a similar idea, writing “As contemporary Iranian filmmaker Nasser Saffarian says, The House Is Black was not made according to a prepared scenario. Most of the film was formed and became a meaningful whole when Farrokhzad finished its editing.” Sheibani [49] adds that “Farrokhzad successfully evades a reporting style of documentary making by viewing the material through her poetic gaze. She problematizes our pre-judgments about notions such as normal/abnormal and beautiful/ugly by showing the leper community just like any other group of people engaged in everyday life.”

With regard to the principles of Islam, the lives of the people in the above examples, and in the content of the film, clearly show integration, interdependence, non-stigmatization, and even the beauty (harking back to Jahiz) of people with leprosy living in a leprosy colony in Iran. Nevertheless, this ideal has often been complicated by external factors such as superstition, cultural norms not grounded in Islam, and lack of accurate scientific knowledge. The producer of the film The House is Black, Ebrahim Golestani, saw the film as conveying a secular critique of people with leprosy seeking to improve their lot through prayer rather than through medical treatment [49], yet as discussed earlier, the Islamic hadith texts actually encourage (if not command) people to seek medical cures, and the film itself does show the people receiving medical attention. Even as family, community, and government in early and current Islamic communities practiced compassionate care for people with leprosy, those same trusted institutions have also sometimes undermined the care of people with leprosy and leprosy related disabilities with their own particular perspectives.

3. Concluding Remarks

We have attempted to draw attention to Islamic values and principles as they relate to the lived experiences of Muslims with leprosy and other or related disabilities, from both a historic and current perspective. To this end, our research has allowed us to educate ourselves while listening to the voices of Muslims with leprosy across a span of more than 1000 years. We are grateful to have had access to important work produced in both academic and non-academic circles, as well as for the important insights from the sacred books of Islam have allowed us to glimpse at the lives of individuals, family members, and communities of people living with leprosy in Muslim spaces. We have also seen that Islamic sacred texts (Quran and hadith) have promoted de-stigmatization and even inclusion of people living with leprosy, and that the Islamic tradition is amenable to revisiting the nuances of these texts in light of modern medical and scientific advances. The fact that the practice within Muslim communities has sometimes not reflected these religious principles highlights the need for improving religious literacy in Muslim societies, and for collaborative efforts between religious and medical specialists. Strong family support structures in the Muslim world have been seen to be a double-edged sword: they can foster greater inclusion of people living with leprosy, but in the absence of religious literacy, they can reinforce cultural stigmas.

Despite the limited academic work and non-academic representations of people with leprosy, we feel that combining Islamic studies with critical disability studies shows a new way to advance “leprosy centered” narratives and policies. To be successful, such initiatives should be undertaken in partnership with individuals and families living with leprosy. Future efforts should identify not only the issues and needs of these individuals but also opportunities to advance the integration and citizenship of this overlooked community worldwide—including those who are of the Islamic faith.

Instead of working in parallel but separately, public health professionals, religious studies scholars, theologians and religious community leaders, and disability studies advocates should engage in collaborative advocacy-based research projects, policy evaluations, and program recommendations. The scope and effect of this emerging work about leprosy and Islam will be determined by whether
disability studies scholars as well as others in fields such as history, anthropology, religious studies, public policy, education, social work, and urban planning can work together to explore current problems and possibilities for improvement through a rights-based, inclusive framework. If we can meet this challenge, we can not only start to make a difference in how leprosy and leprosy policies are viewed, but also help to redesign policies and their implementation in ways that promote a forward-thinking, inclusive agenda.


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