

Knowledge and perception of leprosy amongst high school students in Italy: A survey

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Summary

Objectives This study explores knowledge and perception of leprosy among adolescent Italian high school students. It primarily aimed to survey their knowledge and educate them about the social stigma linked with this infection, both past and present; it also introduced them to the academic research process. Adolescents were selected for the survey to compare the data with a previous survey of adults. The survey was part of an outreach program included in a Marie Skłodowska-Curie Actions project on medical care for people with leprosy buried in leprosaria cemeteries in medieval Europe.

Methods During 2020 and 2021, 15–17-year-old Italian high school students completed 10 questions about leprosy in an online anonymous questionnaire via Google Forms. A final open question asked for five words that ‘leprosy’ evoked in them.

Results 533 students completed the questionnaire. The results demonstrate that leprosy is believed to be a disease of the past and students were not aware of the nature of leprosy, where it is found today, and how it is treated.

Conclusion More work is needed to educate upcoming generations about neglected infectious diseases, like leprosy. This is important to avoid misunderstandings provoking stigma around people who have leprosy today, a disease that can be easily cured.

Keywords: Leprosy, infectious disease, social stigma, education, adolescents

Introduction

Leprosy, also called Hansen’s disease, is a chronic infection that remains present in some parts of the globe.¹ The infection is caused by *Mycobacterium leprae* or *Mycobacterium lepromatosis*; it is not highly contagious. The incubation period can be very long but is, on average, five years. The precise mechanism of transmission is not completely understood. Still, it is generally accepted that it is primarily caused by the inhalation of bacteria-laden droplets from the nose and the mouth of a person with untreated lepromatous leprosy.² The disease affects the peripheral nerves, the skin, the upper respiratory tract, and other parts of the body,

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such as the skeleton, which can all potentially lead to physical deformities. In addition, people with leprosy may develop compromised mental health, partly caused by social stigma.³ Today it is treated with multidrug (antibiotic) therapy.⁴

Leprosy appears to have been relatively common during the medieval period, but societal attitudes towards people affected by leprosy varied. Often, they were regarded as malicious sinners and persecuted and banished from their communities. On the other hand, leprosy was perceived as an act of God, meaning a gift from God.^{5,6} This assumption was based on theological grounds: leprosy was seen as the manifestation of purgatory on earth, and thus the soul of the infected would reach heaven immediately after his or her death. Some sources describe people suspected to have leprosy being subjected to a trial named '*iudicium leprosum*' where they were inspected by a team of lay and medical examiners.⁷ If they were diagnosed with leprosy, they had different options depending on the individual's social status, the resources of the community, or the severity of the symptoms.⁸ In most cases, they had to leave the community and enter a dedicated hospital for people with leprosy, the leprosarium.

In archaeology, the two main direct sources of evidence for leprosy are affected human skeletons and the remains of leprosaria buildings. Bioarchaeologists study human remains and can identify this infection in the bones and teeth of skeletons; knowledge from clinical studies of the skeletal changes in leprosy provides the basis for diagnosis in ancient skeletons.^{9,10} This disease can affect the skeleton in 3–5% of people, but in some studies this figure is higher.¹¹

Until recently, attitudes to people who had leprosy in the past were very negative. While the general belief was that they were banished from their communities and forced to leave their settlements, or segregated in leprosaria, new data from historical literature and archaeology suggest that people with leprosy were more accepted by their communities than has been suggested previously.^{5,12–14} Nevertheless, studies conducted on contemporary populations indicate that many communities still have a negative attitude towards people with leprosy (for instance, see Refs. 15–17). People may be stigmatised, humiliated, forced to leave their jobs and families, and isolated from their communities. In addition, the burden of stigma can extend even to their descendants.¹⁸

With this background in mind, a survey was conducted in Italian high schools as part of an outreach program developed from a Marie Skłodowska-Curie Actions project (grant agreement ID: 844364) entitled *Medical Treatments in Medieval Leprosaria. Exploring Healing Remedies through Dental Calculus Analysis*. The survey aimed to explore what adolescents from a European country (Italy) know about leprosy and what perceptions they have about people affected by this disease, "perception" being defined as how an individual or group sees others (social perception; Ref. 19). Ultimately, this study hoped to develop an academic interest in school age students that would engage them with topics related to history, medicine, and archaeology through being involved with a university research project.

Material and methods

The motivation for the survey developed from one conducted on adults in England as a starting point for a book on leprosy published in 2020.¹⁰ It was noted that there did not appear to be any surveys at that time where knowledge of leprosy had been assessed in the West, although there have been many elsewhere in the world. This 2020 book attempted to explore and dispel the myths surrounding leprosy, such as it is easy to contract, can be inherited, cannot be cured, and all people in the past were segregated from society.¹⁰ Two hundred and seventy participants completed the survey in 2012 and 2013. The same questions used in this previous survey were also used for the current study.

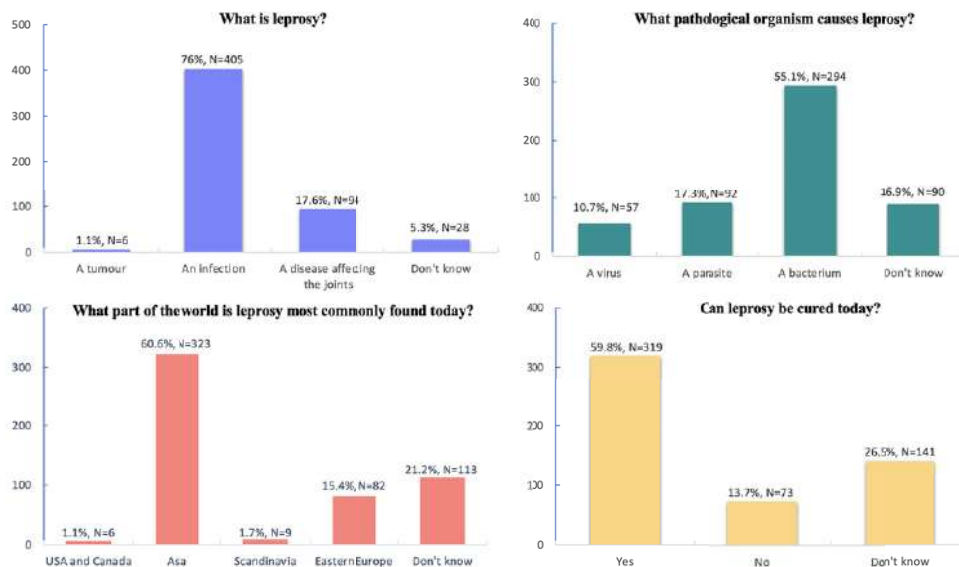


Figure 1. Bar charts illustrating the first four questions of the survey. The vertical axis shows the number of students while the horizontal axis represents possible answers.

The administrations of three Italian schools approved the survey which was conducted between 2020 and 2021 (during the COVID-19 pandemic). A total of 533 students between 15 and 17 years of age took part. To protect the privacy of the participants who voluntarily joined the research, no confidential information was collected. Due to COVID-19 restrictions, the questionnaire was completed online using Google Forms. The schools and numbers of students taking part were (i) the ‘M. Martini’ school in Mezzolombardo, Trento ($N = 54$), (ii) the ‘Le Filandiere’ school in San Vito al Tagliamento, Pordenone ($N = 244$), and (iii) the ‘Leopardi-Majorana’ school in Pordenone ($N = 235$). The survey consisted of ten multiple-choice questions concerning knowledge and perception of leprosy and a final tenth open question in which the students had to write at least 5 words describing what leprosy meant to them.

Results

Question 1. *What is leprosy?* (Figure 1). Most students (76%, $N = 405$) replied correctly that it is an infection, but 24% ($N = 128$) answered that it could be a tumour, a disease that affects the joints, or simply a disease they were not familiar with.

Question 2. *What pathological organisms (“germ”) cause leprosy?* About half of the students (55.1%, $N = 294$) answered that a bacterium causes it. By contrast, the other 44.9% ($N = 239$) thought it was caused by a virus or a parasite, or they simply did not know the answer.

Question 3. *Can leprosy be cured today?* About two-thirds of the students (59.8% $N = 319$) were confident that leprosy can be cured, although the others were not sure about the existence of an effective therapy (40.2%, $N = 214$).

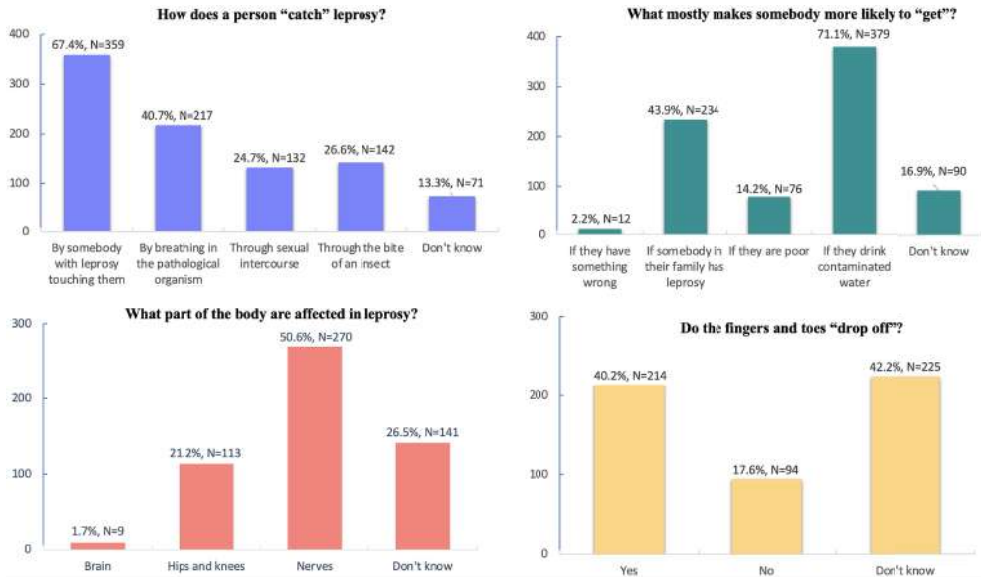


Figure 2. Bar charts illustrating the next four questions of the survey. The vertical axis shows the number of students while the horizontal axis represents the possible answers.

Question 4. *What part of the world is leprosy most commonly found today?* Two-thirds of respondents correctly answered Asia (60.6%, $N = 323$). However, others thought the disease was primarily found in Eastern Europe (15.4%, $N = 82$). Others were not sure and did not answer, and a few thought that leprosy is most seen in the USA, Canada, and Scandinavia (2.8%, $N = 15$) (Figure 1).

The next two questions were designed so that students could select one or two answers.

Question 5. *How does a person “catch” leprosy?* The two most reported answers were: ‘by somebody with leprosy touching them’ and ‘by breathing in the pathological organism’ (Figure 2).

Question 6. *What mostly makes people more likely to “get” leprosy?* Seventy per cent ($N = 379$) answered ‘if they drink contaminated water’ followed by ‘if somebody in their family has leprosy’. Only 14.2% ($N = 76$) thought poverty could play a key role, and 2.2% ($N = 12$) linked the disease with bad behaviours.

Two questions were directly linked to the physical appearance of people with the disease (Figure 2).

Question 7. *What parts of the body are affected in leprosy?* Fifty per cent of students believe that nerves were mainly affected ($N = 270$), and 26.5% ($N = 141$) did not know which part of the body was most involved.

Question 8. *Do the fingers and toes “drop off”?* Only 17.6% ($N = 94$) of the respondents believed that the fingers and toes do not “drop off” from the hands and feet.

Question 9. *Is leprosy described in the Bible?* A large proportion of students (79.4%; $N = 423$) answered yes (Figure 3).

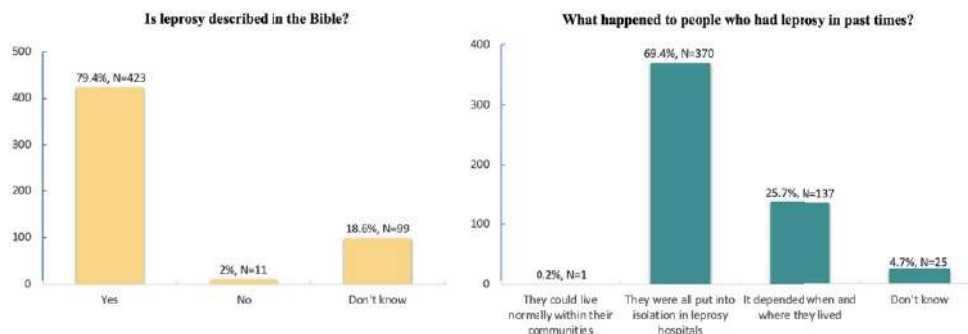


Figure 3. Bar chart illustrating the answers to the two final questions. The vertical axis shows the number of students while the horizontal axis represents the possible answers.

Question 10. *What happened to people who had leprosy in the past?* Two thirds of students (69.4%; $N = 370$) indicated that all people were placed in isolation by being admitted to leprosy hospitals. However, 25.7% ($N = 137$) answered ‘it depended on when and where they lived’, whereas only one student (0.2%) selected ‘they could live normally within their communities’ (Figure 3).

Finally, at the end of the questionnaire, students were asked to write down at least five words that defined what leprosy meant to them or what they felt when they were thinking about this disease. The most cited words were ‘diseased’, ‘isolation’, and ‘infectious’. Other widespread words reported were ‘poverty’, ‘death’, ‘suffering/pain’, ‘disfigured’, ‘dirt’, and ‘dangerous’ (Figure 4). Among these words, 47 students wrote ‘to take care of’, which can be considered the only answer that has a positive connotation. Comparing the results between the schools, there were no differences in the answers given.

Discussion

In exploring knowledge and perception of leprosy among 15–17-year-old students from three Italian high schools, this research found that knowledge about leprosy varies. Teachers and directors of the schools involved were very positive about this initiative since this topic is not included in the official school curriculum (e.g., in biology or history), possibly because, in Europe, it is considered an uncommon disease although there are still autochthonous occurrences in the Mediterranean region.²⁰ However, infectious diseases remain part of the disease landscape in our world today and ideally should be included in school curricula. This is especially important because of the recent COVID-19 pandemic, where knowledge of what causes it, how the virus is transmitted, who is most vulnerable, how people can be protected against the virus, and whether it can be cured are questions that have been, and remain challenging, for people to answer.^{21–23} Importantly, during its height COVID-19 was very prominently reported in the media. Therefore, people across their life course, including adolescents, would have been, and are, very aware of the impact of infections on their families, friends, and human populations. Nevertheless, because leprosy is not a common disease in most of the world’s population, knowledge about the disease has been lost to the general public and medical professionals alike.

Overall, this study revealed that respondents had some incorrect assumptions about leprosy, such as leprosy is still considered incurable, or that social interactions, like a simple touch, can

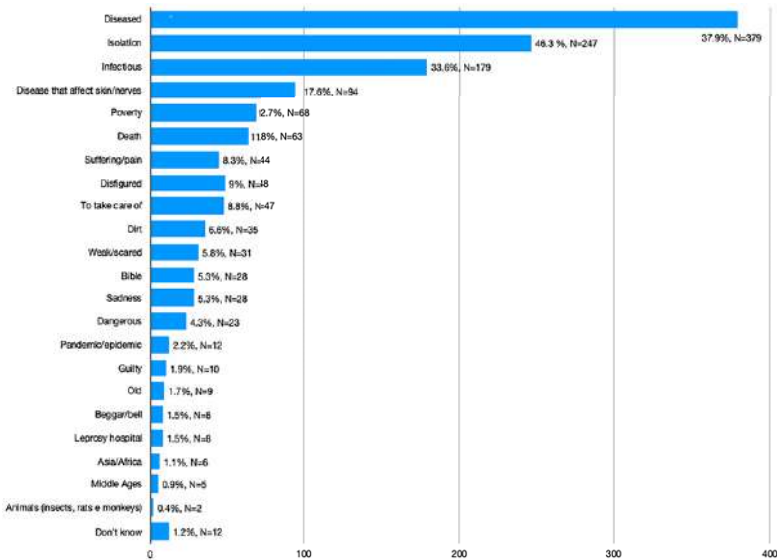


Figure 4. Horizontal bar chart showing the words students indicated to define leprosy and their feelings related to this term.

lead to contracting the disease. Students answered correctly that leprosy is an infection, but many of them did not know what type of pathological organism caused it. This could be due to a lack of knowledge about the biological characteristics of the infection, including the type of organism that causes it. Most students believed that in the past, people affected by this disease were all segregated into leprosy hospitals and thus isolated from their community. It is possible that this idea was exacerbated from experiences of the COVID-19 pandemic where, in many countries, populations were “locked down” for varying amounts of time to prevent infection and/or transmission it to others. It was a coincidence that the survey was completed during lockdown when the students were at home and isolated. Furthermore, during the global pandemic, the media used the word “leper” to refer to people affected by COVID-19 in a negative and very offensive way. At the beginning of the pandemic, the then-Italian foreign minister, Luigi di Maio, said that ‘*Italy should not be treated as a leper colony*’. Immediately, organizations and groups of persons affected by leprosy wrote an open letter to the Italian minister, but no TV programmes or newspapers condemned this inappropriate language or advised the public not to compare COVID-19 with leprosy (<https://zeroleprosy.org/wp-content/uploads/2020/06/Open-letter-to-Italian-Foreign-Minister-Luigi-Di-Maio-1-1.pdf>; see also Ref. 24).

A comparison of these data with the results of the survey of adults ($N = 270$) in England conducted by Roberts¹⁰ revealed that most (80%) knew that leprosy was an infection and that it is most frequent in Asia (68.4%). There were mixed responses about its cause. However, 49.3% thought it was caused by a bacterium, with 21.7% saying it was a viral infection. There were 41.5% of respondents who believed it to be transmitted by breathing in the bacterium, but 22.3% thought it was contracted by touch, and 25.4% did not know. There were very varied responses about who was most vulnerable: people who drank contaminated water (31.5%); if somebody in the family has leprosy (26.4%); and if a person was poor (24.3%); but 17.8%

did not know. Adults believed that the nerves were the most affected part of the body (64.2%), with 15.3% saying the hips and knees, and 16.4% did not know. Nearly half of respondents thought the fingers and toes “dropped off” (44.7%), but 39.7% said they did not, and 15.6% did not know. An overwhelming 72.9% said leprosy was curable, 9.3% said it was not, and 17.8% did not know. As to what happened to people who had leprosy in the past, 45% said they were placed in leprosy hospitals, 51.3% said it depended on when and where they lived, and 1.8% did not know. The final question regarding words that reflected the feelings of these adult respondents about the word “leper”, ‘isolation’, ‘diseased’, ‘disfigured’, ‘stigma’, ‘infectious’, and ‘poverty’ were the top six. In addition, there was an almost overwhelming perception that leprosy is described in the Bible (79.3%). Overall, comparing our data with those collected from adults in England, it was clear that the answers were very similar. The collective response from the adolescents about how leprosy is contracted showed they were not sure. Both groups undoubtedly believed that the fingers and toes ‘drop off’ and that leprosy is described in the Bible. Finally, the main words/phrases that reflected the opinions of both sets of respondents about the word “leper” were negative. Comparisons with other studies showed similarities between this study, the English study, and those conducted in lower income nations.^{22,23,25,26}

Conclusions and recommendations

This study shows how the image of a person affected by leprosy, at least in this research, remains negative and stereotypical. More work is needed to properly inform and educate the public of all ages about infectious diseases still present in the world to help address the social stigma surrounding them. The perception of adolescents is that people affected by leprosy are poor, disfigured, infectious and incurable. Nevertheless, a few students called attention to the need to take care of people with leprosy because they recognised that they could be ‘frightened’ and ‘weak’ and deserved to be assisted and supported by their community. There remains a need to educate all generations across the life cycle further via research and practice in clinical and social sciences, but also through including these neglected tropical diseases in school teaching and medical training. Furthermore, continuing to explain how views about leprosy are changing in history and bioarchaeology through a re-examination of evidence should address the negative perceptions of leprosy held by the general public today, and in the future.

Ethics statement

Directors of the three schools and their teaching boards approved the survey. To protect the privacy of the participants, who voluntarily joined the research after school approval, no confidential information was collected.

Conflict of interest

The authors report no conflict of interest.

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Contributions

EF and CR conceived and designed the research. EF and CR analyzed the data. EF and CR wrote the original draft, and all authors reviewed, edited, and approved the paper.

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