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LEPROSY AND STIGMA IN HISLOP'S *MARIA'S ISLAND*

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ABSTRACT. In this article, we propose a reading of Victoria Hislop's *Maria's Island* through the lens of the medical humanities. The novel belongs to the literary genre of children's literature and, thus, is meant to be read by children. However, its strong meanings make it an interesting read for the adult reader, as well as the scholar in the fields of literary studies, the medical humanities and medicine. The plot unfolds in the small Greek villages of Plaka and Spinalonga (in Crete) and revolves around a leprosy epidemic. As we are going to see, the locals viewed the disease as a "curse" and a "social stigma," and not as a medical condition. After a historical account of the disease, its "shame" and "stigma," we proceed with a detailed analysis of the novel and explain how these notions are manifested. We also analyse how Maria, Anna and Doctor Nikos Kyritsis (three key characters in the story) represent different values and perspectives. On the one hand, Anna reflects the mentality of a conservative society and the view that leprosy carries a social stigma. On the other hand, Maria and Nikos believe that leprosy should be seen like any other disease that needs treatment, and that the leprosy patient is not a "stigmatised" or a "cursed individual." Maria and Nikos represent the medical community in the novel, as Maria becomes a nurse and Nikos is already a Doctor, and show how medicine, compassion and a feeling of understanding create a safe and secure environment for the patient. Memory and flashback are key elements in the story, as Maria, the main character of the novel, explains to her granddaughter what happened in her village many years ago.

KEY WORDS: leprosy, stigma, curse, medical humanities, literature

Introduction. The Novel and the Role of the Medical Humanities

Victoria Hislop's *Maria's Island* (2021) is inspired by the author's novel *The Island* and is an adaptation for a younger readership. However, the deep meaning and the medical connotations make it an enjoyable read for the adult reader, as well. The

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novel is a first-person narrative, and the narrator is Maria Petrakis, who lived with her family in the Cretan village of Plaka. Maria explains how the inhabitants who had contracted leprosy were forced to leave their island and move to the nearby island of Spinalonga. The narrative is enriched, a characteristic of the literary genre, with Gill Smith's colourful illustrations – which make the story more vivid (https://www.victoriahislop.com/marias-island/).

The storyline starts with Rita, a girl of Greek origin who lives in London with her parents, explaining: "Every summer I go with my parents on a long journey by plane and boat to the island of Crete to visit my yiayia (that's Greek for grandma)" (Hislop 2021:7). Rita explains that during her holidays, she and her parents stay with her yiayia and enjoy Greek hospitality. Once, Rita heard her mother asking her grandma if she would like to go with them to England. However, her yiayia replied that she has "too much to look after here," referring to her village. One day though, when Rita and her yiayia were the two of them, the young girl asked her grandma some questions. As the plot unfolds, Rita's yiayia starts narrating her story and shares memories of her youth. With the method of flashback, she takes the reader many years back, when she was still a young girl – during a leprosy epidemic in her village. Rita's grandmother is Maria Petrakis, who explains her special bond with her village, and Doctor Nikos Kyritsis is Rita's grandfather.

If the reader bears in mind that Doctor Kyritsis brings the news of a new pioneer medicine, which cures the population of Spinaloga, then s/he is inclined to say that the action takes place in the 1940s – when the first effective treatment for leprosy had been discovered. As Dobson explains, "in 1941 a new drug called Promin (a sulphone drug) was developed" and had been tested on some patients in Louisiana; the outcome was impressive. This treatment had been followed by "dapsone which could be administered orally rather than by injections" (Dobson 2015: 53). It is also important to note, that Spinalonga was used as a quarantine island for leprosy patients from 1903 to 1957, when the last patients moved to a leprosy hospital in Athens (Spinalonga | International Leprosy Association).

As an interdisciplinary field of research that emerges as a bridge between medicine and the humanities, the medical humanities shed light on Hislop's novel. Frequently nowadays, medical practitioners proceed to cold diagnoses, ignoring the humane face of medicine. The medical humanities can offer an alternative angle, beyond the clinician's cold scientific explanation, taking into consideration the role of the humanities in medical practice. As Bleakley asserted, the medical humanities "can offer a necessary suppleness to a medical education" (Bleakley 2015: 23). The medical humanities deal with the human and his/her ailing condition, and marry fields such as history, literature, philosophy, music, and the arts with medicine to explain an illness

and the illness experience. As such, the medical humanities promote a humanistic approach and interdisciplinarity, through the connection of clinical care with the humanities (Bleakley 2015: 35-36). As a descriptor, the medical humanities include the study of medicine by humanities researchers, explore the role and contribution of the arts and humanities in medical education and accommodate the work of arts practitioners, who deal with the manifestation of illness (Bleakley 2015: 40, 47).

What is perhaps more relevant to our study, the medical humanities emerge as a necessary tool to interpret certain medical connotations in the narrative. The way Maria, as a nurse, and Nikos Kyritsis, as a Doctor, treat patients shows that humane treatment is critical in order to prevent stigmatisation and exclusion. Doctor Kyritsis, who is not a leprosy patient himself, is not afraid of physical contact with patients and ignores beliefs, which undermine certain people.

Stigma and Disease

Hansen's disease (named after the Norwegian physician Gerhard Henrik Armauer Hansen, who discovered the cause of leprosy in 1873) or leprosy as the disease is widely known, is a chronic and bacterial infection, caused by the bacillus *Mycobacterium leprae*. It can damage the nerve, the skin and the bones (Dobson 2015: 41), and is transmittable through the nose and the mouth (https://www.who.int/health-topics/leprosy#tab=tab_1). According to the WHO, the symptoms of the disease can be described as follows: "(1) definite loss of sensation in a pale (hypopigmented) or reddish skin patch; (2) thickened or enlarged peripheral nerve, with loss of sensation and/or weakness of the muscles supplied by that nerve; (3) presence of acid-fast bacilli in a slit-skin smear" (https://www.who.int/health-topics/leprosy#tab=tab_1).

Leprosy is considered an old disease, as it appeared in ancient civilisations, but in Europe, it was a major problem in the Medieval era (Dobson 2015: 41). In the twelfth and thirteenth centuries, leprosy was seen in the same way as plague and the infected were isolated. There were about 19,000 leper asylums in Europe by 1225 to accommodate the infected population. Inevitably, segregation became a normality (Nutton 2011: 46-70; Porter 2011: 176-210). It is also interesting to note that the disease is mentioned in Leviticus, while a type of the disease spread in the Roman Empire, when the troops of Alexander the Great returned from India (Strathen 2005: 70). Yet, there are references to leprosy in Hippocrates and Aristotle, but of course without substantial knowledge (Santacroce et al. 2021: 623-632). Today, the disease is curable and, generally speaking, not a major problem. However, there are cases of leprosy in certain parts of the world –like Africa, Latin America and Asia– and some people still experience the social stigma of the disease and do not follow any treatment (Dobson 2015: 55-56).

The fact that the infected individuals had to leave their homes and live in leprosy colonies, gave the patient the status of stigma and shame. In the nineteenth and twentieth centuries, offshore islands had been used to quarantine the infected population in different parts of the world. This imposed a new reality, as "the question of segregation of the infected raised many sensitive and conflicting issues." In 1948, the name "Hansen's disease" officially replaced "leprosy" for two reasons: in honour of Hansen and his discovery, and also to face the status of social stigma–which became almost synonymous with the disease. However, it is considerably doubtful whether this ever changed, as the name "leprosy" is still widely used in a historical and medical context (Dobson 2015: 41-56).

"Stigma," as a term, denotes degrading marks on the body, with important social dimensions which give an individual a lower social status. Stigma is a social concept, which signifies disgrace and a sense of abnormality within a community. The status of being stigmatised does not simply mean that someone is different, but "discredited, denigrated, devalued and disgraced" (Dolezal 2022: 854-860). Leprosy, like other diseases which carry this status of stigma, is associated with certain challenges for the patient (Northrop 2017: 218-224).

In general, the medical approach to leprosy has changed throughout the centuries, but the social stigma was and still is a fact for certain societies. In the past, people with leprosy had been treated in an inhumane way. The physical impairments caused by the disease resulted in feelings of fear and segregation and patients with leprosy had been forced to live in isolation and die in poverty (Santacroce et al. 2021: 623-632). The fact that the disease becomes too "obvious," affecting the skin, the peripheral nerves and the eyes (Santacroce et al. 2021: 624) means that it can hardly remain unnoticed by others.

Carrying a "terrible disgrace," leprosy patients were forced to live in "quarantined colonies," excluded from their communities. In that way, the healthy population felt safe and protected from an infection with "a strong and bad social stigma." As Santacroce and colleagues explained, leprosy patients had been "ostracised by their communities and families," as there was a fear about the disease – which is still present, through sayings such as: "don't treat me as I have leprosy!" (Santacroce et al. 2021: 629-630).

As one understands, leprosy can result in discrimination and stigma and patients experience pain, anxiety, denial and social exclusion. The fear these people feel forces them to isolate themselves, so that they can avoid rejection and protect their fragile psychological state (Garbin et al. 2015: 194-201). Consequently, stigmatisation becomes a problem with political, clinical and, of course, social dimensions, which ends up being strictly related with feelings of shame. Social exclusion deteriorates the

condition of the leprosy patient and makes the feeling of shame and stigmatisation stronger. Shame becomes an important denominator, as even when a society does not impose isolation, the patient feels the need to hide and isolate himself because of the shame of his condition. Naturally, shame accompanies stigmatisation and becomes another threat for the patient's well-being (Lyons et al. 2017: 208-210). In certain cases, shame becomes a chronic condition and takes the form of a self-stigma (Woods 2017: 251-256).

The stigma that accompanies the disease causes psychological and social concerns to the patient and makes the experience of illness painful. As Dolezal put it, "shame anxiety, or the chronic anticipation of shame, best characterises the first-person experiential dimension of living with a health-related, or health-relevant, stigma" (Dolezal 2022: 855). This relationship between stigma and shame is widely accepted, as shame is one of the negative consequences of stigmatisation. The concern of the patient to be exposed and humiliated becomes stronger, when this is combined with the stigma of his/her condition. Simply put, shame is a "negative self-conscious emotion" and is related to social standards. It could be even seen as an underlying condition, which comes to the surface when an individual considers his presence in a community, in connection with the others' presence (Dolezal 2022: 856). According to Gilbert, the people who feel shame, believe that "there is something actually 'unattractive' about themselves". Patients with specific diseases are very likely to experience this feeling of shame (Gilbert 2017: 211-217).

Leprosy, like other diseases which damage the skin, comes with a metaphorical and a literal stigma: a metaphorical stigma which denotes the social exclusion of the leprosy patient; and a literal stigma because of the marks on the skin. As Connor asserted, the skin becomes "visible on its own account" and it has "come to mean the body itself," even if it is not really the body. It is not "detachable" and "always takes the body with it;" it is meant to protect and connect the body. It reveals situations such as "shock, trauma, grief, fear, anxiety and shame," and, in general, feelings and conditions that sometimes an individual is not able to understand initially (Connor 2004: 9, 21-34, 99). Let alone, when the body becomes "victim" of a disease such as leprosy, where someone is alarmed with the first marks on their skin, like Maria and her mother (not with this order though) in the novel.

The Manifestation of Leprosy and Its Stigma in the Novel

The fear of the disease is obvious in the early stages of the novel, through the reactions of Maria's sister, Anna. When their mother is announcing to the two sisters that their father is taking some "sick people" (Hislop 2021: 26) to the quarantine island (Spinalonga), Anna's reaction is indicative of her inner thoughts: "Sick people! You mean lepers!" shrieked Anna. "He's taking lepers to the island? Why? Where's Mr Li-

dakis? That's *his* job!" (Hislop 2021: 26) Anna is "shrieking," when she hears the news that her father is helping Mr Lidakis, who is in charge of this burden. In addition, although the mother is very mindful and describes these people as "sick people," Anna is challenging that. Her statement "you mean lepers," implies that Anna does not see these people as "sick people," but as a special group of patients. The notion of stigma, which will be augmented later in the story, is implied here, as Anna sees the lepers as a distinct group of people. It is considerably doubtful whether she really cares about her father's health or the fact that the stigma of the disease can affect herself and the name of her family. The repetition of the word "lepers" shows that she is upset:

> Her fears become stronger, despite her mother's efforts to explain to her:
>
> "He'll catch leprosy!" Anna shrieked. "He'll be cursed! His hands will fall off! He'll go blind! He'll crippled."
>
> ***
>
> "Has Mr Lidakis got leprosy? Has he caught it? I bet he has! And now our father will catch it too." (Hislop 2021: 27)

Anna is in a panic: she refers to the consequences of the disease for an individual and her statement that their father will be "cursed," alludes to certain religious traditions. For many years, leprosy was considered "a curse of the gods, a punishment for sin, or a hereditary condition" (Editorial 2019: 378). For instance, The Third Lateran Council, presided by Pope Alexander III in 1179, announced the patients of leprosy "dead unto the world but alive unto Christ," and that they should be isolated (Strathen 2005: 70). But beyond such religious interpretations, leprosy is seen as a "social curse" as well by certain cultures. In any case, leprosy patients are considered outcasts and their disease a "curse." This "stigmatised 'leper' identity" becomes a dividing line (Jay et al. 2021: 276-287), which links to the status of the "cursed." As Jay et al. asserted, "people affected by leprosy belong to one of the most stigmatised groups worldwide, and experience social curse effects" (Jay et al. 2021: 284-285).

In the story, Anna reflects the view that leprosy is a curse and a social stigma and not an actual disease – which explains her previous statement, "you mean lepers." Anna relies on social and perhaps religious standards, which have been imposed by a conservative society without scientific validity. The following day, Maria is curious to learn about the disease and find out whether her sister overreacted or not. So, when she asks her father about leprosy, he gives a simplified–but still convincing description:

> "What people are afraid of is partly right," he explained. "Sometimes the disease eats away at your body. In the end you can lose your fingers and toes because you can't feel them any more, so you can't work or even walk." (Hislop 2021: 34)

Maria confesses that although she "had assumed [her] sister was overreacting as usual", "now [she] realised she wasn't" (Hislop 2021: 34). In addition, her father's statements show that the leprosy patient has no contact with the outside world. In particular, he says: "And that's all I know really;" and "I left the couple at the quayside over there and then they went through a tunnel that leads into the rest of the island. I didn't see anything else. Or anyone else" (Hislop 2021: 32-33). It seems that there are two separate worlds without any connection. Her father's mention of the tunnel, which leads inside the "other" island, sounds like an entrance into another world, almost a passage to death. This tunnel that leads to the unknown, creates an atmosphere of secrecy.

Although Anna, under normal conditions, would run and hug her father, this time her reaction is different:

> She hesitated in front of him. Normally she would have given our father a hug before leaving, but I could see that she still had her suspicions and thought that if had been with leprosy patients, he might be able to pass on the disease. (Hislop 2021: 33)

Anna is suspicious and sceptical, even worried that she might contract the disease for her father; thus, her concerns about herself prevail over her love for him. The fact that leprosy is a disease that separates families, is implied, if not manifested, through Anna's attitude and fears of stigmatisation.

Anna's attitude shows that people frequently adopt views about stigma without medical knowledge. Let alone, if stigmatisation and the "cursed" status are encouraged by the administration and the religious leader of a 1940s Cretan village:

> That Sunday, the priest read out a passage from the book of Leviticus in the Old Testament. It said that anyone with leprosy was cursed, that they were unclean and that they should be sent out of the village.(Hislop 2021: 35)

The community of Plaka was already worried, as the disease was spreading quickly. However, this fear was augmented by the preaching of the priest, who, without the appropriate scientific knowledge, called leprosy a curse and those who contracted the disease "unclean." So, the locals had the grounds to proclaim the leprosy patients as outcasts: "You see?" [Anna] whispered. "What did I tell you? It's a living death"

(Hislop 2021: 35). Even if Maria does not share –to the same extent– these fears, she is still concerned about the disease and its impact on her family:

> My fear of leprosy and whether my Dad might have caught it was greater than before, but I still did not really understand what it was. (Hislop 2021: 35)

However, although Maria heard about the terrible consequences of leprosy by her father, her sister (who spreads rumours and superstitious beliefs) and the religious leader of her community (who is not able to see the disease as such, but as a "curse"), she states that she still does not know what the disease was. Thus, she adopts a different and critical stance. Her statement shows that as opposed to the society of Plaka, Maria is looking for answers through scientific and medical explanations.

The announcement that someone has leprosy is a painful moment. This is evident when Dimitris, Maria's close friend from school, finds out that he contracted the disease:

> My mother came out from behind the screen. She was very pale…
> ***
> I saw Dimitris come out and immediately dash through the door. I chased after him and soon found him in the corner of the school yard, his face hidden beneath his cap. He was crying.
> ***
> I sat next to him on a low wall, put my arm round him and felt the sobs that rocked his body. (Hislop 2021: 43)

Despite her mother's fear, reflected on her pale face, and Dimitris' fear, who ran away upset, Maria still considers him her best friend. She sits next to him and gives him a hug, showing that nothing has changed for her. Her words "Dimitris…Dimitris… it's all right. It's all done now" (Hislop 2021: 43) show her compassion and quality as a person. Maria becomes a voice of protest in the small society of Plaka, as she does not comply with unsupported views, which lack scientific validity. As we are going to see later, Maria is looking for facts and truths that only medicine can provide.

Her mother's instructions, though, come as a reminder for Maria about the two worlds and the dividing line leprosy imposed:

> "Maria, please get up and go and play with your other friends," she said sternly. "I need to take Dimitris home. If they ask, tell the children that I will be back very shortly and lessons will start then." (Hislop 2021: 44)

Worried and in a stern tone, the mother tells Maria to play with her "other friends." Thus, the mother-teacher stresses the two estranged worlds, and that Dimitris is not a member of the school community anymore. The intention of Maria's mother to start the lesson only when Dimitris is removed from the school, shows in the clearest way that there is a change of status for Dimitris: a transition from a healthy status to illness. Driven by her instinct, the mother-teacher tells Maria to play with the other children in order to protect her from a contagious disease.

Maria's emotional state, when Dimitris had to go to Spinalonga, is indicative of an individual's feelings when s/he has to say goodbye to a beloved one: "In my whole life, nothing so terrible had happened. My best friend had caught the incurable disease and soon he would leave for ever" (Hislop 2021: 47). As a real friend, Maria is not worried about her own health and whether she contracted the disease or not. Her inner thoughts show her real interest in Dimitris, and what makes her upset is that he is leaving. What is more, Maria seeks the truth about the disease not in the gossip of Plaka or the misleading preaching of the priest, but through medicine and science:

> The doctor had given my mother a leaflet about leprosy, which now lay on the kitchen table. Finally, my curiosity could be satisfied.
> ***
> There was information about using sulphur to disinfect anything that had been touched by someone with leprosy, but the leaflet kept on repeating that anyone diagnosed must be isolated. Isolation was the only solution. There was no cure.
>
> I put the leaflet down. I wished I had not read it at all. (Hislop 2021: 49-50)

Maria confirms what she already knew: there is no cure for leprosy; it affects the skin of the patient; and the only solution is isolation for the infected. However, Maria is reading the doctor's leaflet to satisfy her "curiosity" – as opposed to the society of Plaka, which relies heavily on pseudo-scientific explanations. Even if Maria read about "isolation" as the only way to prevent the spread of the disease, the leaflet does not refer to "stigmatisation" or a "cursed" status.

A new shock comes for Maria, when she sees a mark on her mother's neck:

> "Mum. There is something on your neck. A mark."
> She hurried across the room to the mirror.
> "It's round the back," I said.
> She craned her neck to try and see. (Hislop 2021: 51)

Maria's mother is trying desperately to see this mark. The stretching of her head shows her concern. The lack of physical contact between the healthy and the ill population is apparent, when Maria's mother and Dimitris are going to Spinalonga: "On Monday morning, she left the house without kissing us goodbye because she was afraid we would catch leprosy. She was wearing her favourite blue shawl" (Hislop 2021: 57). Maria's mother left the house without kissing her two daughters, in order to protect them from a contagious disease. However, when Maria's mother is ready to go with Dimitris, there is physical contact, as the two of them belong to the world of sickness:

> Dimitris was waiting in the street outside and I saw my mother take his hand. His parents then went back inside their house and shut the door. It gave me a funny feeling, seeing my mother holding my best's friend's hand and knowing that she should never again hold mine. I wanted to run after them.(Hislop 2021: 59)

The reader can assume that the two islands, Plaka and Spinalonga, become symbols of two distant worlds: health and illness, respectively. Physical contact between the two worlds is not possible and only people from the same world can socialise and touch each other. The way Dimitris' parents "went back inside their house" and then "shut the door", shows that they are worried more about the social stigma, rather than the health of their son. The locals comply with the consequences of the disease and accept isolation without protests. Still, driven by feelings of love and compassion for her two beloved ones, Maria "wanted to run after them." In Maria's "funny feeling," when she saw her mother and Dimitris going together, one detects jealousy and the complaint of a child who knows that she will never touch or see her mother again; something she mentions later: "I felt a pang of jealousy at the thought of Dimitris getting all of our mother's attention and then I felt ashamed" (Hislop 2021: 63).

The communication Maria has with her mother is reminiscent of the dividing line that separates Plaka, the world of the healthy, and Spinalonga, the world of sickness:

> After a few weeks Mr Lidakis brought us an envelope. It had come from Spinalonga and had a really strange smell, just like a stink bomb.
>
> "It's been disinfected," he said to our father. It was what they did with letters from the island to get rid of the bacteria. (Hislop 2021: 62)

Although the disinfection of communication material is expected and a usual measure for public health, the smell which Maria describes seems like the odour of a distant world – even though Spinalonga is not very far away from Plaka (Hislop 2021: 62). (Maria waves to her mother every morning before school. On another occasion,

Maria's mother waved her shawl and then Maria, Anna and their father waved back, see Hislop 2021: 66). The disinfected envelope does not have the smell of just a disinfectant, but it becomes a symbol of illness and contagiousness; a reminder of the fragility of the human body.

In addition, Maria explains that she and Anna were seen by the others as stigmatised; something though, she does not reveal to her mother, as she wants to protect her from rumours:

> I didn't tell her that some of the children ran away every time either Anna or I were anywhere near them. I had heard the word "stigma" used by grown-ups but now I really knew what it meant. If you had a relative with leprosy, people shunned you. Anyway, I mentioned none of that. The most important thing was to tell her that I always waved as I left home to go to school. (Hislop 2021: 64)

The notion of stigma becomes clear, in the way the other children avoid the two sisters. The reader is inclined to make a connection with covid-19, a topical public health issue, and how the status of quarantine affected certain societies and their way of thinking. Maria's statement that she heard about "stigma" before but only now knows what it means, shows her transition from the random and the unspecified to the new status of the "actual stigma," even if it is her mother who caught the disease.

Nevertheless, if there is someone who feels this stigma and shame stronger is Anna:

> A few months later, I was tidying up the things Anna had left behind and I found the pictures that Mum had sent to Anna stuffed in a drawer. I knew then how ashamed she was that Mum was on Spinalonga. (Hislop 2021: 73)

When Anna turned eighteen, she married Antonis and moved in with him. However, she left behind the pictures her mother sent to her, as she felt ashamed of her mother's disease and the social stigma. As soon as Anna started a new life with her husband, she wanted to leave her family and her past behind. The pictures which are hidden at her family's house show that she almost wants to forget her previous life.

On the other hand, Maria, who continues exchanging letters with her mother, notices some changes in her drawings and handwriting:

> A year or so after, I noticed a change in my mother's drawings. They became less detailed.
> ***

> Even her handwriting had begun to alter.
> (Hislop 2021: 74)

Even if she is not aware of that (since she describes this change as "strange", see Hislop 2021: 74), Maria refers to the way leprosy affected her mother's skin and health in general. So, when her mother's condition deteriorated, Dimitris started writing her letters (Hislop 2021: 74).

Although the death of their mother was a shock for the family, Anna had other major concerns:

> Anna was seven months pregnant when Mum died. When she was told the news, all she said was that she did not want her child ever to know that her grandmother had died of leprosy. The stigma was all she seemed to care about. (Hislop 2021: 78)

Despite the news of their mother's death, Anna cares about the stigma and wants her child to grow up in a safe environment. She doesn't want her child to learn anything about the disease of her mother and believes that the stigma of leprosy is a terrible thing. Instead of mourning for her mother's death, she is preoccupied with how to protect herself, her child and her new family from the social stigma of leprosy.

By rejecting her mother, Anna shows her fear of the disease and the social stigma. However, as the reader can surmise, this discrimination and separation of families was expected in the small society of Plaka, as Dimitris' family treated him in the same way:

> He told me that he had received a letter from his parents who had asked him to stop writing. They no longer wished to communicate with him as the stigma was too great. I was shocked that anyone could reject their own child and avoided Dimitris's parents after that. I knew that they were not the only people in the village who wanted nothing to do with leprosy. There were several who crossed the road to avoid me, simply because my mother had died of the disease. (Hislop 2021: 79)

In his letter to Maria, Dimitris explains that he experiences a similar situation, with the difference that he is the carrier of the disease – whereas in the case of Maria the carrier was her mother. In any case, Dimitris' story shows the difficult state of the leprosy patient, especially when s/he has to face rejection by his own family. Dimitris' case is the manifestation of discrimination, as he is rejected by his own parents — despite his young age. Even if death is unavoidable, the way his parents treat him shows that he is already dead for them. The idea of mourning is completely absent from the narrative and even if Maria says that she was "shocked" with the news, this should

not be seen as a surprise. According to her narrative, many people crossed the road every time they saw her. Stigmatisation is certainly the case in Plaka and the locals had to comply with this new harsh reality.

Maria's already tense relationship with her sister becomes worse, when Anna notices a mark on Maria's leg:

> "Maria! Look at your leg!"
>
> She snatched her child into her arms.
>
> "You know what that looks like?" she said, pointing.
> "I won't say the word in front of my daughter. But you know *exactly* what it is!"
>
> Without saying goodbye, she immediately left the house. My father and I were shocked both by her rudeness, and also by what she had noticed.
> ***
> And there it was: a mark about the size and shape of a strawberry. (Hislop 2021: 80)

Maria's and her father's shock is double: because of the mark and because of Anna's reaction. Anna's "rudeness" shows that after the death of their mother, she is still afraid of the disease and the social stigma. As soon as she sees the mark on Maria's leg, she is trying to protect her child and herself; thus, she "snatched her child" and "immediately left the house," without saying goodbye. She doesn't even say the name of the disease in front of her daughter, as she believes that in that way she is protecting her. Her statement "you know *exactly* what it is" sounds like a reminder of the "curse," which her mother had and it has passed now to Maria. As Maria explains near the end of the story: "Some people never changed their views, however. Anna never invited us to her home and, since the day she noticed the mark on my leg, I have not seen my niece" (Hislop 2021: 123). Anna sees the disease without a concrete scientific explanation and insists on explaining the disease as a "curse" or a "social stigma." Thus, she hides the memories from her mother and terminates communication with her family.

When the story begins Maria is a teenager, but when she arrives at Spinalonga, she is a grown-up woman:

> Even before the boat was tethered, I could see Dimitris waiting for me at the entrance to Spinalonga. More than half a decade had passed since we had seen each other but we hugged just as we had done as children. We were overjoyed. (Hislop 2021: 84)

The status of her friendship with Dimitris did not change with the passage of time. Although everyone else avoided Dimitris throughout his stay at Spinalonga, as Maria explains "[their] letters had kept [them] very close." Despite the difficult circumstances and the distance, their friendship remained unaffected, as Maria ignored the social stigma of the disease.

Arriving in Spinalonga, Maria sees an organised society with houses, shops, a bakery, a coffee-shop, a school and a hospital; some of them mentioned in her mother's letters (Hislop 2021: 84-89). Maria's decision to work at the hospital as a nurse, is indicative of her good nature and willingness to help others:

> I spoke to one of the nurses and said that I would be very happy to help out. The next day, I was instructed on how to clean and dress the sores that so many people suffered from, and after that I began to go every day. (Hislop 2021: 89)

Leprosy cannot prevent Maria from having a normal life at her new home. Soon, she becomes one with the society of Spinalonga and helping those in need becomes her priority. Maria does not treat herself as an ill or stigmatised individual and remains active, at the service of the local hospital. With the passing of time, she became an experienced nurse and "started teaching other people how to nurse the sick." In addition, she made "detailed notes on patients' symptoms and treatment" (Hislop 2021: 91). If in Plaka, Maria showed her disagreement with the pseudo-scientific and superstitious beliefs about leprosy and sought answers in medicine, in Spinalonga her thirst for knowledge became stronger. As a nurse, Maria keeps her records about the disease and makes her own observations. She is part of the medical community and hopes to cure the disease and reduce its social stigma.

The arrival of a determined medical practitioner brings fresh air to Spinalonga and makes Maria hopeful about the future. This medical practitioner treats patients with respect and shows that the medical community does not see the leprosy patient as a person of lower social status. Driven by his passion for medicine and ignoring beliefs about stigma, he is happy to meet the patients of Spinalonga:

> "I am Doctor Kyritsis. Very nice to meet you," he said.
>
> "I am Maria. And this is Kyria Vasso," I said, indicating the patient I was helping. (Hislop 2021: 94)

As opposed to Anna, Dimitris' family, and as the reader can assume the society of Plaka in general, Doctor Kyritsis does not avoid physical contact with patients. As a medical practitioner, he sees the disease as such, and not as a curse or a social stigma.

Doctor Kyritsis knows that the leprosy patient is not an outcast, but someone who needs to be treated like patients of other diseases. He even shook hands with Maria and made her wonder: "Why would anyone who was well want to touch me?" Maria was "astonished" (Hislop 2021: 94). Beyond his medical training, Doctor Kyritsis adopts a very humane approach, as he is compassionate with the patients and understands their illness experience.

In addition, his explanation to Maria about the reasons of his stay at Spinalonga shows his real interest in the cure of the disease:

> "I am going to live here," he said. "I want to study the patients and find out about each one of them and about how their leprosy progresses. It is important for my research. Do you keep records?" (Hislop 2021: 94-95)

Dedicated to his research, Doctor Kyritsis wants to study each patient separately. He sees them as individuals and not as a stigmatised and isolated group. Maria's reply "I told him that I had started making notes on some of the patients in the hospital" shows her determination to help, but of course that the two of them think alike. Maria and Doctor Kyritsis represent the medical community, promote research and knowledge, and doubt superstitious beliefs, which result in social stigma and discrimination. Even if they cannot cure leprosy yet, they can ease the patient's suffering: "We could not stop people dying, but at least we could relieve their discomfort" (Hislop 2021: 96).

A glimpse of hope appears, when Maria reads in an article that the world medical community "had made a discovery" and after Doctor Kyritsis returns to Spinalonga from his journey. Determined to implement the new treatment, Doctor Kyritsis and Maria "make a list of the patients whom [Doctor Kyritsis] wanted to take part in an 'experiment.'" The news was that "there was a new drug but it had not been tried on many people" (Hislop 2021: 98). The patients who had been selected were happy to take part in this experiment, as "Everyone on Spinalonga knew that this was [their] only hope." Ignoring potential risks, they participated in this medical experiment "for the rest of us" in Maria's words (Hislop 2021: 100).

As opposed to the society of Plaka, where the locals had stigmatised the infected ones and attached to their families the social stigma of the disease, the society of Spinalonga is connected, and people care about each other; the result of their common illness experience. While in Plaka one sees discrimination and exclusion, in Spinalonga people understand that they have to coexist in order to survive. They feel and behave as a real community, and collectiveness becomes their priority. They agree to be "guinea pigs," (Hislop 2021: 100) as what really counts for them is the sur-

vival of their community. They did not lose hope and agreed to take part in this medical experiment, as they knew that medicine is their only ally. The reader sees here the collision of two different worlds: Plaka, where discrimination is a critical determinant, and Spinalonga, where people care about each other without social limitations.

Driven by this collective spirit, Maria wants to take part in the experiment, even though Doctor Kyritsis did not put her name on the list. Although in the beginning the result of the treatment was not the expected one (Hislop 2021: 102-103), after some days Maria's marks were gone:

> I saw a strange expression on his face: a mixture of joy and disbelief.
>
> It was a few moments before he could speak.
>
> "It's gone. The patch has disappeared."
>
> "Disappeared?" I echoed. "It can't have disappeared."
>
> "Well, there is nothing on your leg. Not even a small mark." Doctor Kyritsis held my hand and I could feel him trembling. "Maria, I think the drugs have worked." He was obviously happy but I could see that there were tears in his eyes.
>
> "You mean I am…cured?"
>
> He nodded.
> (Hislop 2021: 105)

Doctor Kyritsis is initially surprised, after he sees that Maria has no marks on her body, but immediately after he is filled with happiness. Doctor Kyritsis' reaction shows that although he never ceased to hope for a permanent cure, the efficacy of the drug was unprecedented. Maria is also happy and surprised with the results of the new drug and her question shows her hesitance to believe the outcome. However, Doctor Kyritsis' positive reply comes as a confirmation of her cure and signifies the end of an era, as leprosy was not an incurable disease anymore. Later, the drug was used for the other leprosy patients of Spinalonga and most of them had been cured (Hislop 2021: 110).

Despite the inventions of medicine, the social stigma remained and people saw those who returned from Spinalonga with scepticism:

> I had a letter from my father telling me how excited he was that I was returning. But he also warned that there was an atmosphere of fear in Plaka. People were still afraid of leprosy even though there was now a cure. (Hislop 2021: 111)

People were not convinced yet that leprosy was curable and not ready to accept Maria and the others back. A striking example was the teacher of Plaka:

> Dimitris had written to the teacher in Plaka to ask if he could come and work there, but she had refused to let him anywhere near the school. The disease had been cured but the stigma remained.(Hislop 2021: 111)

The teacher's refusal to accept Dimitris at the school shows that stigmatisation remained a painful reality. Despite Dimitris' cure, the teacher remained attached to superstitious beliefs – disregarding the medical developments. People, like the teacher, continued seeing leprosy as a curse and social stigma, and as Maria explains "there would be new difficulties and stigma to face," returning to Plaka (Hislop 2021: 110).

There is a happy ending though, as beyond hers and the others' recovery Maria accepts Doctor Kyritsis' marriage proposal. In her words: "I looked back at Spinalonga and then at Nikos. In a single moment, I had found both love and freedom" (Hislop 2021: 118). Maria and Nikos, a couple now, would travel the world (India, Nigeria, Brazil) to spread the drug. As Maria says, they explained to people about leprosy and that it is "a matter of bad luck, not a punishment from God." As she also says: "In many places, the shame and stigma of leprosy finally began to lift. For a long time, people found it hard to accept that it is a disease like any other which is spread with bacteria and is now completely curable!" (Hislop 2021: 122) Dedicated to medicine and driven by their genuine thirst for knowledge, Nikos and Maria wanted to help humanity. As opposed to the local society of Plaka, where fear and stigmatisation were basic determinants, the two of them promoted collectiveness and medical knowledge and, thus, contributed to the reduction of stigma.

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On the whole, the novel revolves around leprosy and stigma, and the consideration of the disease as a "curse" by a certain community (Plaka). A basic element in the plot is the contradiction of Plaka with Spinalonga, where people coexist and collaborate, sharing the same stigma – which, in fact, brings them together. The contradiction becomes stronger, through the views of three key characters: Maria, Anna and Nikos.

Initially, the reader sees the contrast between Anna and Maria. Although Anna believes that she knows about the disease, in reality she reproduces rumours and pseudo-scientific and superstitious beliefs. While Anna takes for granted the preach-

ing of the religious leader on a medical condition, Maria questions these anachronistic views and seeks information through medicine and relevant leaflets. A second contrast appears, when Maria contracts the disease. While Anna leaves the house immediately with her daughter and avoids any physical contact with her family, Doctor Kyritsis is not afraid of physical contact and shakes hands with Maria. So, while Anna sticks to views which lack scientific validity, Doctor Kyritsis, as a skilled practitioner – who attends the medical community's meetings and keeps himself updated with medical developments, relies on medicine. He is a humane and compassionate practitioner, who respects each patient.

Consequently, his attitude opposes the notion of contagiousness, which is present throughout the story and has been misunderstood by people like Anna and Dimitris' parents. These people are ignorant of medicine, but at the same time unwilling to learn and treat a disease as a medical condition.

Conclusions

Hislop's novel is a fascinating and inspirational story, useful for the scholar of the medical humanities and the medical practitioner. This is a story, which can introduce the adult reader and the younger reader, alike, to a literary depiction of leprosy and the history of the disease. In particular, the younger reader (given that the novel belongs to the literary genre of children's literature) can investigate and explore the medical connotations of Maria's story. The medical humanities provide the appropriate tool to learn about the disease and its history, going beyond literary manifestations. In addition, the medical humanities prove to be an ideal tool to analyse literature–regardless of literary genre and readership.

Perhaps, it is an exaggeration to claim that a medical humanities course should be introduced in secondary education, for example. However, in an era where universities introduce medical humanities departments and courses, relevant literature, like *Maria's Island*, can be used in schools, as a means to promote interdisciplinarity and show the next generations that medicine and humanities can coexist in a productive way. This is a story of survival, but also the story of a young girl who overcame the limitations of her conservative society, and became someone who changed the world. Maria becomes an example for her granddaughter Rita, the "audience" of the story, but also an inspirational personality. She is also a symbol of inclusiveness, as even if she was forced to say goodbye to her beloved ones – she never felt that the world of Plaka and the world of Spinalonga are two separate worlds.

Thus, in the same way the medical humanities can be the bridge between medicine and humanities, Maria and Nikos became the bridge of Spinalonga with the outside world. In the end – when they travel to other countries, they become symbols of change, compassion and inclusiveness. Even if people like Anna are not willing to

change and remain prisoners of their superstitions, Maria and Nikos show that there is always hope in the world.

References

Adas Saliba Garbin C et al. (2015) The stigma and prejudice of leprosy: influence on the human condition. *Revista da Sociedade Brasileira de Medicina Tropical* 48(2): 194-201.

Bleakley A (2015) *Medical Humanities and Medical Education: how the medical humanities can shape better doctors*. New York, NY: Routledge.

Connor S (2004) *The Book of Skin*. Ithaca, NY: Cornell University Press.

Dobson M (2015) *Murderous Contagion: a human history of disease*. London: Quercus.

Dolezal L (2022) Shame anxiety, stigma and clinical encounters. *Journal of Evaluation in Clinical Practice* 28: 854-860.

Editorial (2019) Abandoning the stigma of leprosy. *The Lancet* 393: 378.

Gilbert P (2017) Shame and the vulnerable self in medical contexts: the compassionate solution. *Medical Humanities* 43(4): 211-217.

Hislop V (2021) *Maria's Island*. Illustrated by Gill Smith. London: Walker Books.

Jay S et al. (2021) From social curse to social cure: a self-help group community intervention for people affected by leprosy in Nepal. *Journal of Community & Applied Social Psychology* 31: 276-287.

Lyons B, Dolezal L (2017) Shame, stigma and medicine. *Medical Humanities* 43(4): 208-210.

Northrop JM (2017) A dirty little secret: stigma, shame and hepatitis C in the health setting. *Medical Humanities* 43(4): 218-224.

Nutton V (2011) The rise of medicine. *The Cambridge History of Medicine*, 46-70. Edited by Porter R. Cambridge: Cambridge University Press.

Porter R (2011) Hospitals and surgery. *The Cambridge History of Medicine*, 176-210. Edited by Porter R. Cambridge: Cambridge University Press.

Santacroce L et al. (2021) *Mycobacterium leprae*: a historical study on the origins of leprosy and its social stigma. *Le Infezioni in Medicina* 4: 623-632.

Strathen P (2005) *A Brief History of Medicine: from Hippocrates to Gene Therapy*. London: Robinson.

Woods A (2017) On shame and voice-hearing. *Medical Humanities* 43(4): 251-256.

Internet Sources:

https://www.victoriahislop.com/marias-island/. Accessed on 10 February 2023.
Spinalonga | International Leprosy Association. Accessed on 11 February 2023.
https://www.who.int/health-topics/leprosy#tab=tab_1. Accessed on 10 February 2023.