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Corresponding Author:
mariano.martini@unige.it
mariano.yy@gmail.com

Medical Humanities & Tuberculosis: thinking with Stories during Recent Years

Mariano Martini
Department of Health Sciences, University of Genoa, Genoa, Italy

Francesco Brigo
Department of Neurology, Hospital of Merano (SABES-ASDAA), Italy

Davide Orsini
University Museum System of Siena (Simus), History of Medicine, University of Siena, Italy

ABSTRACT

Medical Humanities & Tuberculosis

Tuberculosis (TB) is one of the oldest diseases known to affect humanity and is still a major public health problem. Today TB is one of the ten most frequent causes of death in the world. It is caused by the bacillus Mycobacterium tuberculosis, isolated by Robert Koch at the end of XIX Century when it was one of the most common diseases in the population.
TB has caused millions of deaths in various historical periods. A social disease, TB has featured prominently in Medical Humanities (MH) on account of its great impact on literature, the arts, music etc... There is an excellent relationship between the arts, literature to TB, and the influence and effects of TB on the humanistic disciplines. Art, music, literature are expressions of emotions, feelings, passions, but they also talk about empathy. Through our path, we will try to show that the approach to TB should be part of the medical education, through the study of MH and also through listening to a patient's story.

Key words: History of Tuberculosis - Medical Humanities - Narrative Medicine - Ethics - Storytelling - Arts - Literature

Epidemiological background and current situation

Tuberculosis (TB) is still one of the world's most serious public health threats and a major cause of avoidable deaths in the adult population.

It is caused by the bacillus Mycobacterium tuberculosis, isolated by Robert Koch at the end of XIX Century when it was one of the most common diseases in the population.

A century ago, in Italy and in most other western countries, four out of every thousand people died of TB each year, and most of these deaths occurred among young adults[1,2]. Since then, better hygiene and living conditions and the introduction of efficacious treatment have markedly improved the situation[3,4].

Nevertheless, TB continues to be a global problem; it is one of the most frequent and serious infectious diseases worldwide, and millions of new cases are reported each year[5].

In 2020 alone, 33,148 cases of TB (7.3 cases per 100,000 population) were reported in 29 states of the European Union and/or European Economic Area (except for Latvia, which did not provide data).

In reality, however, although overall notification rates and infection rates are either declining or stable in most countries, they are not yet in line with the objective of eliminating TB by 2030[6].

Moreover, it must be borne in mind that the measures implemented in 2020 to curb the COVID-19 pandemic may have impacted on the surveillance and the services dedicated to tuberculosis.

The "Global tuberculosis report 2021" indicated that in 2020 TB was the second-leading cause of death (after COVID-19) due to a single infective agent – a truly striking statistic…!

Unfortunately, the COVID-19 pandemic has rolled back years of progress in the struggle to control TB. The impact of the pandemic has been most clearly manifested by the sharp fall in the global number of notified cases of TB and new diagnoses.

According to the available data, it is estimated that 5.8 million new cases of TB were diagnosed in 2020: an 18% drop from the 7.1 million diagnosed in 2019. This drop is in contrast with the rising trend in notifications observed between 2017 and 2019.

The countries that contributed most to the global decrease between 2019 and 2020

India	Indonesia	The Philippines	China
41%	14%	12%	8%

These countries, and another 12 countries, accounted for 93% of the global reduction of 1.3 million cases. It is interesting also to observe that a similar phenomenon (relationship between Covid and TB nowadays) occurred at the beginning of the twentieth century on the occasion of the well-known Spanish pandemic (1918)[7]: "Regarding the

rapid decline in tuberculosis mortality in the two years following the end of World War I, Filippo Neri, Health Officer of the Municipality of Siena and assistant of Achille Sclavo[8], at the Institute of Hygiene of the University of Siena, wrote: "This decrease certainly cannot depend on the return to normal living conditions, because hardship in this two-year period remained as severe as it had been during the War. An explanation of the rapid decrease of tuberculosis mortality can be supposed only if we keep in mind the 1918-19 flu pandemic. [...] If we admit - as it can be easily assumed - that a large number of deaths from influenza had occurred in tuberculosis patients, whose compromised immune system was easily overtaken by the influenza virus, we have a better understanding of what triggered the rapid decrease in tuberculosis mortality between 1919 and 1920"[9].

Introduction

One of the most ancient diseases known to mankind, tuberculosis (TB) remains a serious public health problem[10]; today, it is one of the 10 leading causes of death in the world.

It is caused by the bacillus *Mycobacterium tuberculosis*, which was isolated by Robert Koch[11] at the end of the 19th century[12].

At that time, tuberculosis was one of the most widespread diseases in the population. Also known as "he thin disease", it has caused millions of deaths in various historical periods.

A social disease, TB has featured prominently in *Medical Humanities* (MH) on account of its great impact on literature, the arts, music, opera, the theatre, the cinema, etc… Indeed, it was a *"fascinating"* disease that might also be defined as a *"common disease"*, in that struck the whole of society, regardless of class, in various historical eras. A disease that inexorably reached thousands of people, and which still today wreaks its relentless devastation, albeit affecting fewer people than in the past and being amenable to decidedly better treatment. TB displays an undisputed relationship with art, literature[13], music, history and human sciences. Indeed, the influence and effects of tuberculosis on the humanistic disciplines has truly constituted an evocative aspect that is rich in prospects for study and research of a broad multidis-

Fig. 1. Heinrich Hermann Robert Koch (1843-1910)

ciplinary nature[14]. Art, music and literature express emotions, feelings, passions and mystery; but they also speak of empathy, which is fundamental aspect of the doctor-patient relationship[15].

The Narrative Medicine Approach in the Treatment of Tuberculosis

Our study retraces the healthcare pathway of patients affected by tuberculosis and through this study we tried to illustrate the fact that the approach to tuberculosis, and to other diseases, not only infectious diseases, must be part of the training of doctors and other healthcare workers.

Through the study of Medical Humanities, and through listening to the stories of patients, we can grasp many aspects of their diseases and better understand their state of both physical and mental health. The interior story, or narrative structure of the life of a patients can also help to make sense of their experiences, and these can contribute to curing the patient and/or improving his state of health[16,17].

Narrative-based medicine (NBM) is the application of narrative ideas to the practice of medicine. There is no accepted definition of NBM[18,19].

Rita Charon says that *it is medicine practised with narrative competence "to recognize, absorb, interpret, and be moved by the stories of illness*[20].

The definition arrived at in 2014 by a committee of international experts was that NBM is "a fundamental tool to acquire, comprehend and integrate the different points of view of all the participants having a role in the illness experience[21].

Today, medicine is becoming increasingly "scientific", being based chiefly on statistical and epidemiological evaluations. Thus, the language of medicine and biomedicine frequently fails to provide useful information on the subjective experience of the patient, on her family situation and on society's true awareness and perception of disease. Medicine should also take into account stories and narratives; the patient who turns to the doctor and who lives through an experience of disease describes not only his illness, his symptoms and his discomfort, but also his feelings and fears and the expectations that accompany his state and the course of the disease[22,23].

Narrative Ethics and Patient-Physician Relationships

A "patient-physician relationship" exists when a physician serves a patient's medical needs and it is considered to be the core element in the ethical principles of medicine. In particular "doctor–patient relationship" is usually developed when a physician take care of patient's medical needs through check-up, diagnosis, and treatment in an agreeable way.

The patient must not therefore be regarded only as a number or as a case of a disease on which healthcare professionals focus exclusively; "he/she" is, above all, a person…!

By contrast, current healthcare systems and the new biomedical technologies tend to give rise to an approach whereby the doctor concentrates more on the patient's pathology and less on the person.
It is an approach that tends gradually to downplay the personal aspect, partially or totally, thereby leaving the patient to assume a "more passive role". Moreover, the doctor's objective examination also tends to be subordinated to technology. Instead, the doctor should listen to the patient; even today, this is a key point in the doctor-patient relationship and may have extremely important diagnostic implications[24].
In this process, the patient's narrative constitutes a unique and "personalised" gateway to that interior set of elements which can help to orientate the therapy itself.
"Recounting" is an indispensable ingredient of "narrative-based medicine"; indeed, allowing the patient to talk to the doctor about her illness, to describe not only her symptoms but also the feelings that accompany them – fantasies, fears and expectations – is not only an act of courtesy on the part of the doctor[25].
Current technology and instrumental and laboratory examinations may well enable doctors to frame and fine-tune the diagnostic, clinical and therapeutic investigation.
Nevertheless, modern medicine, just like the medicine of the past, should seek to involve the patient to a greater extent by giving him the chance to recount even his most intimate and personal history, thereby enabling the doctor to know the person behind the disease.
In this regard, it is essential for doctors to make an effort and try to understand what the patient says, in order to undertake efficacious treatment. This involves applying the skills of text analysis in every area of their professional activity: when they read the case records, listen to the patient, train students and write their own reflections…
By developing their capacity for attention and representation, they fulfil their duties towards the patient.

Patient's narrative and the milestone of storytelling

Contact and connection are precious moments, as they enable the doctor to grasp the patient's suffering and hence to alleviate it[26]. The ability to listen is therefore a fundamental quality that the doctor must have.
Moreover, our intimate personal narrative may become *storytelling*. Thus, an individual account becomes "collective", and the story of one person may sometimes become the story of many; in any case, it should prompt reflection on the part of the reader.
Through narration, the patient can more accurately convey what she is going through.
While patients certainly need a precise diagnosis and therapy to follow, they also need acceptance, comfort, support and hope in the face of their illness; patients must therefore be able to trust those who guide them.
Illness inevitably deprives a person of something important; it engenders profound sadness, which is often difficult to express and to manifest…[27,28,29].

For us, listening to some patients and doctors recount their experiences of such an insidious and subtle disease as tuberculosis was a truly unique experience; it also enabled us to improve our knowledge of the disease itself from other points of view.
Indeed, the narrations that we listened to, regarding the personal situations linked to this disease, allowed us to gather information that we could cherish and exploit in our future activities, aware that every single case has its own peculiarities and unique features.
Many people are under the misapprehension that tuberculosis has been eradicated, that it is "a disease of the past". Unfortunately, this is not the case; even today, millions of new cases and a large number of deaths are registered each year.
Indeed, the story of tuberculosis is endless, running through millennia. It is to be hoped that this insidious disease will finally be eradicated in the coming years[30].
We listened to the accounts of patients, doctors and other people involved in tuberculosis. Whether rendered by individuals who had experienced the disease personally, by those who had lived through it beside a sick person, or by healthcare professionals, these accounts spontaneously reveal some important aspects of the disease.
In truth, many of these aspects are not always clearly grasped, even though they constitute pieces of the mosaic that makes up the disease.
The International Conference on Primary Health Care, (Alma-Ata, 6-12 September 1978)[31] declared the need for urgent action by all governments, all health and development workers, and the world community to protect and promote the health of all the people of the world, hereby makes the following It emerged as a major milestone of the twentieth century in the field of public health, and it identified primary health care as the key to the attainment of the goal of Health for All.
In particular the Article 4 of the "Alma- Ata Declaration" proclaimed that:
"The people have the right and duty to participate individually and collectively in the planning and implementation of their health care".
Almost half a century has passed since the publication of this solemn document. Today more than ever, the core of health must still be the person; it is the person who stands at the centre of the health system, and health care must be provided for the entire population, without distinction.

Conclusions

Each of these accounts expresses a sensitivity that helps us to better understand the breadth of this disease: its impact on society; the stigma that still persists today, and the isolation and solitude that accompany it. Above all, it enables us to understand an indispensable aspect: the centrality of the person.
The term "tuberculosis patient" is often used glibly and without thinking. However, a patient suffering from tuberculosis, just like any other sick person or person with a disability, is, first and foremost, a person…!

Is there a difference between saying "disabled" and "person with a disability"? Yes, there's a big difference; in the first case, the person is identified with his/her disability, while in the second, the emphasis is placed on the person, regardless of his/her disability. [Bebe Vio][32]

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