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## The Role of Medical Humanities in Prevention and Treatment of Patients With Chronic Diseases

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### ABSTRACT

#### **The role of Medical Humanities in chronic diseases**

In the field of prevention and treatment of patients with chronic diseases, biomedicine often shows its inability to be effective on a clinical level, despite its extraordinary scientific growth. Through the analysis of a clinical vignette, the paper illustrates the skills and the solutions that could be applied to obtain awareness and compliance in chronic patients, using the expertise we can obtain from Medical Humanities.

**Keywords:** Medical Humanities - Chronic diseases - Prevention - Communication - Education - Awareness - Stigma

## Introduction

Medical Humanities (MH) have long been considered an additional component in medical training. While doubting their usefulness as an essential tool in the care process, MH have been added as an ancillary subject to “humanize” a medicine that is too technological, or to bring prestige to a field of knowledge becoming too barren or technical.

However, in the field of prevention and treatment of patients with chronic diseases, biomedicine – despite its extraordinary scientific growth – clearly shows its inability to be effective even at a clinical level, when it does not provide skills aimed at humanizing the approach to the patient.

The entire Italian Healthcare System, as well as the training of healthcare workers, have been structured since their origins to treat mainly patients with acute diseases, who need rapid and prompt intervention. Along with this organization, the well-known and formally criticized disease-centered model was developed, coupled to biomedical data. The structure of this system today is undermined by the rise of chronic non-communicable diseases and of preventive medicine. The most striking demonstration of the inability to cope with such issues emerged in the case of the vaccination campaign for COVID-19, where biomedicine showed the best of its technical capabilities by creating effective vaccines against COVID-19 within a few months, but then showed itself unable to manage vaccine hesitancy in a society characterized by a deep crisis of trust in science<sup>1,2</sup>.

Non communicable chronic diseases currently represent the leading cause of death globally and have an incidence in Europe of 80%, expected to increase, according to the most recent epidemiological projections, with the growth of the elderly population<sup>3</sup>. To obtain optimal results in the management of patients with chronic diseases in terms of adherence to dietary and lifestyle programs, treatment compliance and achievement of therapeutic targets, new models should be applied. These models need to be based on an integrated approach, that requires the patient’s active participation in the diagnosis and treatment and which includes educational interventions aimed at increasing knowledge of the disease, of its evolution and risk factors<sup>4</sup>. Although there is a growing awareness of the need for a paradigm shift that brings the patient as a person at the center of the care process, biomedicine indeed lacks some essential skills to support patients in their prevention and treatment path, to enhance their autonomy, but at the same time to increase their health culture and awareness, in order to achieve good clinical outcomes.

In this paper we will show what contribution MH can provide in reframing the approach to patients with chronic diseases and which kind of skills they can deliver. Using an empirical and problem-based approach, we will analyze the issue through the discussion of a clinical vignette, representing a common clinical situation.

Clinical vignettes are patient-related scenarios that have educational value for a wider audience. Medical education has used the clinical case as a teaching tool since William Osler advocated bedside teaching at the turn of the 19th century<sup>5</sup>, and probably long be-

fore. In its simplest conception, a teaching case is a patient's story, shaped to illustrate or highlight some aspect of medicine – the natural history of a given disease, how to build a therapeutic relationship between clinician and patient, or how to properly examine a patient – that the clinician can use to improve her/his fund of knowledge and clinical skills. Carolyn Jeffries and Dale W. Maeder define vignettes as incomplete short stories that are written to reflect, in a less complex way, real-life situations in order to encourage discussions and potential solutions to problems where multiple solutions are possible<sup>6</sup>. Usually employed in clinical teaching<sup>7</sup>, clinical vignettes could fit perfectly to analyze which skills MH could provide to healthcare workers who deal with patients with chronic conditions and how they give a soundly grounded approach to new models of management. Here we will focus on data which are not related to the clinical condition of the patient, but to the context of care and to the strategies that could be implemented to obtain awareness and compliance in chronic patients.

### **Clinical vignette**

Mrs. S., who has had fatigue, dry mouth and frequent urination in the past three months, at her husband's insistence, goes to her General Practitioner (GP), who prescribes blood tests. Mrs. S. is anxious, she doesn't like to go to the doctor and is unfamiliar with her GP. She rarely goes to the GP's office to have prescriptions for reimbursable medication or for a medical certificate. The results of the blood tests reveal that the blood glucose and triglyceride values are out of the norm, the GP then recommends further tests. After the results of the new tests, Mrs. S. meets again her doctor, who tells her about the diagnosis: a type 2 diabetes. The doctor explains to Mrs. S. that the treatment for her diabetes, still in a mild form, consists first of all in adopting an appropriate diet and in a lifestyle change that includes regular physical activity. This will contribute to a reduction in body weight, which is essential to obtain the control or even the improvement of her condition. The doctor has a long queue of patients waiting behind the door, he has made the diagnosis, given the therapeutic indications, set the appointment for the next visit, yet he has the feeling that the question remains unsettled: the patient will probably not follow his indications, the diabetes will get worse and have more serious effects on the patient's health.

The defeat in front of a patient who does not want to follow the therapeutic indications is intense: the physician can clearly see which is the right choice and the negative consequences of a wrong choice and feels upset.

Two thoughts are likely to cross the physician's mind – they are conflicting thoughts, but they often coexist –:

1. The patient is free to choose, if she doesn't change, it's her fault and she will pay for it.
2. What else could I do to help her?

Our analysis of the problem will revolve around these two questions, because the solution lies, to some extent, in a widespread and systematic use of MH in the training of healthcare workers and in the analysis of specific issues.

### **Guilt, stigma and responsibility**

Let's start investigating the first reaction of the physician – “The patient is free to choose, if she doesn't change, it's her fault and she will pay for it.” –, using the tools provided by Bioethics, Cultural Anthropology and History of Medicine.

The notion of guilt and punishment related to the phenomenon of disease has gone along with the history of Western society since the ancient age. In the archaic Greek world, the idea of disease as a punishment for guilt appears in the first book of the *Iliad*<sup>8</sup>, which presents disease as a supernatural phenomenon that occurs inside, but that comes from the outside and is due to human guilt arousing divine wrath<sup>9</sup>. In the archaic age an evolution of this notion of disease already takes place, as in the myth of Pandora the disease becomes an autonomous entity, detached from divine causality, but remains a demon that strikes randomly for a generic fault of humanity, comparable to a sort of original sin. Although in the classical Greek age the disease becomes an entirely natural phenomenon, in fact the tendency to attribute to the disease the connotation of punishment for a fault remains a constant of the Western culture and is strengthened by the Christian culture (e.g., for sexually transmitted diseases). Even today, at a time when the pathogenetic mechanisms of diseases are known, the propensity to link some disease states to the idea of punishment for a guilt remains. The persistence of these structures can be explained with reference to some basic psychological mechanisms that are triggered in the face of disruptive and partly uncontrollable natural phenomena such as disease. We can observe in these cases the need to seek a meaning in terms of punitive justice – illness as a punishment for risky behavior or for socially reprehensible behaviors – or to put in place apotropaic mechanisms – controlling uncontrollable events through actions –. If the history of medicine makes clear the persistence of such structures and the underlying motivations, bioethics helps us to understand the need to put aside any form of moral judgment towards the patient. Without denying or diminishing the prognostic relevance of risky behaviors, it should in fact be emphasized that it is of paramount importance to unhook the objective finding on a clinical level, from any moral judgment for self-inflicted pathologies and risky behaviors.

It is therefore crucial to clarify what we mean by responsibility and to pay attention to the notion of guilt, often related to stigma. This consideration becomes all the more important if responsibility for risky behaviors or self-inflicted pathologies becomes a criterion for evaluating access to health services in the event of limited resources. Some countries with a Welfare State system in some ways similar to the Italian one, such as Great Britain, have already moved in this direction, excluding from free access

to specific health services those considered responsible for their health condition<sup>10</sup>. According to proponents of this view, if you could have foreseen that your choices posed a risk to your health and made different, healthier choices, you should be held responsible for the outcome. Depending on further considerations, this might take the form of treatment denial, lower-priority access or additional financial costs following treatment. Indeed, such thinking may influence the practice of conditional access to healthcare, where patients are denied the full package of available care until they have taken certain preventive measures such as losing weight or quitting smoking. Although such policies are often justified by reference to effectiveness, in some cases there may be latent assumptions of responsibility underlying them<sup>11</sup>. Moreover, some exclusionary policies are justified by reference to both patient obligations and costs to taxpayers<sup>12</sup>. The problem was more evident in the case of access to intensive care for subjects who refused to be vaccinated for COVID-19<sup>13</sup> and permeates the debate on liver transplantation for subjects with alcohol use disorders (AUD)<sup>14</sup>. In these contexts, it is agreed that the assessment for access must be made in terms of survival benefit and that the assumption of risky behaviors – such as relapse into alcohol consumption – can only be considered if they affect provably survival benefit<sup>15</sup>. In the case under analysis, however, we are in the field of using treatment resources that are not dramatically limited and therefore evaluations aimed at excluding subjects with a more reduced benefit do not come into play. Any exclusion of the patient from access to clinically appropriate treatments would therefore be a serious damage to the patient's right to health and would be based exclusively on a discriminatory moral judgment.

Instead, the notion of an ethics of responsibility should be introduced, emphasizing the impact of our choices on ourselves and on the community<sup>16</sup>. Responsibility from an ethical point of view should not be confused with the concept of liability in legal terms, which implies the idea of punishment. Under an ethical point of view responsibility is intended as the ability to answer for one's behavior, giving reasons for it and accepting the consequences. The notion of responsibility, however, is related to freedom and autonomy<sup>10</sup>. The person can be truly responsible for her own choices if she has been properly informed and if she is actually free in her choice: free from physical, psychological or socio-economic needs. Evidence available<sup>17</sup> suggests a high occurrence of mental disorders in chronic diseases: some of these disorders do not make the subject free in health choices (e.g., eating habits or lifestyle in the case in point). In order to make the subject capable of a responsible choice, it is therefore necessary to implement, both in the prevention phase and in the integrated management phase, a complete assessment of the factors that may affect the freedom of choice, advancing a patient's empowerment process.

Empowerment<sup>18</sup> is defined as the process through which the patient acquires knowledge of the problem and strengthens his own resources that can be implemented to obtain the skill necessary for the self-management of the disease and therapy (self-care),

actively and consciously participating in the therapeutic choices, often by means of passages of increasing complexity. These steps include elementary health education, nutritional and sometimes cognitive-behavioral interventions.

### **Managing emotions and compliance**

What if Mrs. S. has no apparent mental disorder? Let's try to answer to the second question: "What else could I do to help her?".

The recognition of certain conducts as pathologic behaviors (e.g., Binge Eating, Depression, Alcohol Use Disorders) that affect the patient's ability to make a free choice is an essential first step, but it is not enough because we cannot pathologize every divergent choice. It is easier to categorize every risky behavior (e.g., for Mrs. S. an unhealthy diet) as the result of a pathology, because this fits better in the treatment schemes for which doctors have been trained, but the reality is that when it comes to risky behaviors we are faced with a continuum that goes from conscious choice to serious behavior disorder, with a very wide range of nuances in between.

Prescribing a medication is easier for the physician: it is better suited to the extremely short times of outpatient visits and similar to what he's been trained for. On the other side, also the patient expects a traditional path of diagnosis and prescription of a drug treatment, with a quick return to ordinary life. It is much more difficult to change diet or lifestyle than to take a drug, because it is a long-term change and not a one-off action. The lifestyle of a person is the result of beliefs, cultures, values and above all of multiple habits that the person acquires over time and maintains mainly in order to make her life easier: a lasting change becomes a stress and a source of anxiety. Emotions therefore take centre stage in the patient's choice of adherence to the diet, and these emotions have to be managed, not only in the case of pathological behaviors. Although in this context the key role must be played by psychology, with an active and systematic involvement of psychologists in the care pathways, however MH can also provide a relevant contribution. In fact, they allow healthcare workers to be trained in understanding the individual and subjective dimension of the experience of disease, restoring a more complete image of the emotional, cultural and social impact of the process of care.

The key problem, in fact, is that in the treatment of chronic diseases and in preventive medicine psychosocial factors play a significant role in adherence to treatments, in the construction of a therapeutic alliance, in the self-management of the disease, in the quality of life, in the response to treatments, in the evolution of the disease and, finally, in the economic costs associated with disease itself.

### **Reframing the context: towards a real person-centered model**

Chronic diseases and preventive medicine have brought the patient to the forefront as the main player of a condition that lasts over time and requires an adaptation process,

an active and conscious role, the support of other people (caregivers), a good alliance with health professionals on shared goals. Hence, the management model changes: a patient-centered model is needed, based on an integrated approach that requires the patient's active participation in the diagnosis and treatment process and which includes educational interventions aimed at increasing knowledge of the disease, risk factors connected to it and understanding of its possible evolution.

This is perfectly in line with the definition of Person-Centered Care (PCC) given by the Institute of Medicine (IOM), which identifies it as one of the six domains of quality care. According to IOM in fact, PCC entails emotional support, physical comfort, information, communication, education, continuity and transition, coordination of care, family involvement and access to care<sup>19,20</sup>. Data show that PCC improves clinical outcomes<sup>21</sup> and alleviates anxiety<sup>22,23</sup>; it enhances adherence, improves recuperation, and reduces readmissions of patients<sup>24,25,26</sup>.

With this new patient-centered model the physician, expert of the disease, the patient, expert of the illness and the family and the social context, experts of the sickness, cooperate in setting up an effective care relationship. The patient's and the family's agenda – everything that characterizes them, their culture, their language, the metaphors they use, the interpretation of the morbid event, their experience, their anxieties, fears, expectations, needs and resources – become part of the communication process. The patient is actively involved by the physician and participates in the decision-making and therapeutic process, with a complementarity of skills.

The Italian National Chronicity Plan (PNC) of 2016<sup>27</sup> tried to meet these needs. It defines the “challenge to chronicity” as a “system challenge”, which “must go beyond the limits of the various institutions, overcome the boundaries between health and social services, promote integration between different professionals, attribute an actual and effective centrality to the person and his care and life project”. The PNC, paying attention to both the prevention phase and the integrated management of the patient, puts the person and not the disease at the center of the healthcare system, pointing out that the way the person and her caregivers deal with the problem – expected to be long-lasting – affects the results of treatment, the burden of disease, the human and economic costs. The PNC therefore has an agreeable theoretical framework, but has not yet been enforced by the Italian Regions.

Although in theory a transition to a patient-centered model, widely known in MH, is shared by all the stakeholders, actually the policies implemented are struggling to take off, due to economic and organizational issues, but also because a profound rethinking of the whole system is necessary to reframe care in a new paradigm. Even assuming that these economic and organizational obstacles can be overcome, however, it will be equally important to act thoroughly on the mindset of healthcare workers, who are still tied to a disease-based model, also due to inadequate university training. A deep change of the system of care, therefore, cannot fail to rely on an appropriate education of health-



care workers, that envisages an approach to medicine and treatment that really puts the person at the center from the earliest stages of training. In this respect, the contribution of MH becomes pivotal in the process of cultural transformation of the medical class: without such conversion any attempt to transform the system will be pointless.

## Conclusions

The analysis carried out shows that in this moment of radical shift, Medical Humanities, with their problem-based and interdisciplinary approach, play a relevant role. They can no longer be an ancillary discipline serving a medicine that remains firmly anchored only to biomedical data. They need to become a structural element for the development of models and care processes that are able to fully involve the patient and regard him as a whole. If medicine will not be able to take this further step in its evolution, it will run the risk to be ineffective – both in terms of prevention and therapy – in all the therapeutic interventions which are strongly conditioned by the behavior and long-term choices of the patient.

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