# *FEAMC symposium: Challenges of Competence and Compassion in Contemporary Medicine*

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# **Hepatology, Liver Transplantation, and Compassion**

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# **EXTENDED ABSTRACT**

# **Developments and Challenges in Contemporary Hepatology, the Need for Compassion**

## The discipline of hepatology has seen amazing progress over the past few decades including major paradigm-transforming changes. (1) Running from the minuscule (sub)cellular, organ, and organism-systemic realms, up to the societal levels. Quickly expanding genomic and epigenomic discoveries, enabling a much deeper and complex understanding of diseases' pathways, establishing novel, evidence-based classifications of the ‘traditional’ and newly discovered liver diseases that allow their truly customized and effective diagnostics, treatments, and prevention (concepts of ’personalised’ or ‘precision medicine’). Indeed, nowadays liver research, strongly augmented by Big Data and artificial intelligence exploitation helps to clarify better how the environment, microbiome, social interactions, and even parental behaviours may influence various gene expressions and physical developments in an individual, both in health and in disease. Advances in some hepatology areas, such as the development of highly effective oral therapies for hepatitis C and hepatitis B (incl. effective vaccines for the latter), successful therapies for some of the inherited metabolic (incl. ‘orphan’) and autoimmune diseases, as well as extraordinary improvements of management of advanced liver cirrhosis and its complications, novel treatments of hepatocellular carcinoma (HCC), and the liver transplantation long becoming a standard treatment in end-stage liver disease, among many other developments, substantially changed the field of liver diseases and how the discipline is practised. Interestingly, with some diseases more successfully managed, other ones have become more prominent (e.g., both alcoholic and non-alcoholic steatohepatitis/fibrosis/cirrhosis; toxic liver injury due to medical drugs, herbal ‘medicines’, and environmental pollutants).

## However, despite all the progress achieved, the overall health care and societal burden (morbidity, mortality, economic consequences, incl. liver diseases related health expenditures, etc.) of liver diseases is considerable and increasing. Both in developed and developing countries. (2, 3) They bring about broadly felt worries, fears, and scores of human sufferings, including (premature) loss of life (and substantial worsening of its quality). Each liver patient with a serious, especially advanced disease embodies a complex set of unpleasant physical and mental symptoms and is usually in varying need of individually tailored, personally offered support and genuine compassion of ‘his’/’her’ physician. The bond between the liver patient and ‘his’/’her’ physician tends to be especially strong (and positively enhance the patient’s compliance).

## On the other hand, sometimes due to various pseudo-professional myths and still rather poor information on liver diseases among the public, liver patients are facing scores of popular prejudices (about ‘origins’ of their diseases), unfair judgements, and stigmatization (some examples see below), making the mentioned need of adequate support and true compassion even more important.

## Thus, liver diseases and their management pose considerable challenges to contemporary medicine and health care, and the often much strained health care systems and respective allocable resources.

**The stigma of a Liver Disease**

## As mentioned above, liver diseases are considered to be stigmatizing the patient, and even his/her family. It is a well-documented problem in certain liver pathologies, but it is thought to be more general. Within the general public, it is broadly known that some liver diseases may be associated with alcoholism, drug abuse, or certain risky (or even ‘immoral’) behaviours (such as promiscuity, etc.), people may bear various prejudices and may be keen to make unfair judgements against those suffering from particular liver disease, even if it is caused by other than the patient’s ill-behaviour related etiologies. Thus, the patients affected by hepatitis C and B are stigmatized irrespective of the way of acquiring the virus and those with liver cirrhosis regardless of the aetiology of their original liver disease (e.g., genetic-metabolic, autoimmune etc.). Unfortunately, on top of the wrong attitudes and behaviours of lay persons, liver patients sometimes suffer even from the inappropriate comments and behaviours on the part of unethically acting health professionals.

## For example, the frequency and features of stigma perceived by the liver patients suffering from non-alcoholic fatty liver disease (NAFLD) and their quality of life were recently evaluated by the research group from the Hepatology Department of Hospital Clínic de Barcelona, through a specific questionnaire devoted to four different domains: stereotypes, discrimination, shame, and social isolation. In a series of 114 patients with NAFLD, seven out of ten patients felt stigmatized. (4)

## Thus, as already indicated, patients with liver diseases, especially those in advanced or terminal stages of liver cirrhosis, are in special need of personal psychological support and compassion that must be provided to them by their physicians, nurses, and other health care professionals. The properly informed, compassionate patient-physician/nurse/other health professional relationship is both a true need of a liver patient and may substantially contribute toward a successful course of the therapeutic management of his/her disease.

# **De-Stigmatization of Primary Biliary Cirrhosis (now Cholangitis) (PBC)**

During about the last decade, both because of the encouraging scientific advances (bringing novel, effective treatments) and greater attention being given to the patients' views and their empowerment (also due to the successful activities and advocacy of liver patients' organisations (e.g., ELPA – European Liver Patients Association, and its national member organizations)), a seemingly minuscule change of the name of one of the serious, progressive liver diseases has occurred: Primary Biliary Cirrhosis (PBC) has been re-named to Primary Biliary Cholangitis (PBC). This small change in the name has some critical, positive implications for the patients. Most importantly, it removes from them the stigmata of cirrhosis and its implications of alcohol abuse, and the stigmata of the PBC’s formerly rather poor prognosis. It also reminds the patients that they may live (reasonably) well with this disease, not necessarily die of it. This de-stigmatization may even improve PBC patients’ opportunities in the workplace and their everyday social lives. When the leading personalities in this exciting field of hepatology were addressing this paradigmatic change with a mobilising appeal: “*Thus, we sincerely call on all medical professionals and all patients and their families and friends worldwide to use from this moment on the name ‘‘primary biliary cholangitis’’ for the disease known by its abbreviation PBC! We owe this to our patients and to further our role as caring physicians.*” (5), one of the substantial underpinnings of it could be recognized as the compassion of the “caring physicians”.

# Or, as the great ‘Apostle of Nations’ – St. Paul put it: *Be kind and compassionate to one another, forgiving each other, just as in Christ God forgave you.* (Ephesians 4:32)

**Compassion in Liver Transplantation**

Liver transplantation (LTx), since being performed firstly ever in 1963 and firstly successfully in 1967 by Thomas E. Starzl (1926 – 2017) at the University of Colorado Health Sciences Center, has become a standard treatment procedure in end-stage or peracute liver diseases or liver injuries. Albeit being one of the most complicated and prolonged abdominal surgical interventions, connected with its risks, it offers nowadays to the (appropriately indicated) patient a very good prognosis of success (short and long-term survival), including the subsequent major improvements in his/her quality of life. The field of LTx, albeit deemed already much advanced and successful, does see even nowadays numerous changes, and challenges. Both at the medical, as well as ethical level. Even a brief analysis (including the still existing very problematic situation in China (6)), would go much beyond the realm of this contribution.

From a long list of ethical/moral issues encountered in LTx, let us focus just on two chosen examples to illustrate, how compassion is possibly a major contribution towards an adequate professional dealing with them.

Firstly, the situation of an ongoing indication for LTx in a particular patient. Besides the pertinent medical (almost ‘technical’) aspects, sometimes also the aetiology of the liver failure in the patient is (even not explicitly, but knowingly) present at the spot, allowing some stigmata mentioned above to leak in, or even to possibly influence the inner attitudes of professionals taking part in the patient's care and the necessary decision making leading to the LTx indication. This may be even more prominent in the liver diseases that tend to be perceived as kind of mostly self-inflicted by the patient (e.g., alcoholic cirrhosis, cirrhosis due to hepatitis C in a former drug addict, etc.). Moreover, the patient is usually well-aware of these aspects of the situation, while his/her wrong behaviour might be the issue of a distant past, but also being the case of a very recent (e.g., considering LTx in acute alcoholic hepatitis). While the professional medical and ethical course of action and decision-making is paramount in these situations, the room for compassion is recognizable here as a humane and Christian-underpinned opportunity.

Secondly, the situation of a patient with end-stage liver disease living enlisted on the ‘waiting list (WL) for LTx' for already some time. Due to the well-known shortage of suitable organs for LTx, his/her life-saving procedure is being more and more delayed in time, and his/her state of health deteriorating. Moreover, he/she observes his/her fellow ‘WL peers’ dying from various acute deadly complications. (The situation might be further sharpened by consideration of putting the LTx candidate down from the WL due to his/her worsened state of health when LTx becomes contraindicated). Again, the need for a compassionate attitude and care from respective physicians, nurses and other health care professionals is of great importance (and humane/Christian opportunity).

## **In conclusion**, let us end on a positive note. When giving various pastoral instructions to Timothy, the already cited ‘Apostle of Nations’ – St. Paul wrote to him also this advice: “*Stop drinking only water and use a little wine because of your stomach and your frequent illnesses.*” (1 Timothy 5:23), remembering to us that if used wisely (i.e., moderately) the wine can serve us (almost) as a remedy. And, also as a good means to cheer up the hearts of the people: Notably, the first miracle of our Lord was done (upon the intercession of His Holy Mother) at the wedding in Cana of Galilee it being the abundant gift of ‘good wine’ to people celebrating the marriage (John 2:1–11). And a note on stigmatization: our Master was often unfairly judged (by Scribes and Pharisees) because of sharing the meals and drinks at the tables in the ‘homes of sinners’, e.g., in His own words: “The Son of Man has come eating and drinking, and you say, behold, a gluttonous wine-drinking man, a friend of publicans and sinners.” The 'people of good will' know that He did it out of His extraordinary humane-divine compassion. Ours is the obligation to 'go and act similarly'. To be compassionate, as He was compassionate.

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