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Special article

Europe's hepatitis challenge: Defusing the “viral time bomb”[☆]

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Since its foundation in 2005, the European Liver Patients' Association (ELPA) – a not-for-profit-organisation with 21 members across Europe – has been at the forefront of raising awareness of liver diseases, in particular hepatitis, throughout the EU. In line with the main challenge for hepatitis carriers, which is to “become a patient”, ELPA calls for targeted screening of risk groups in order to facilitate early diagnosis and, if appropriate, treatment. To this end, ELPA and its members have embarked on a multi-level lobbying campaign, involving EU and national policymakers, liver specialist associations and public health experts.

First successes include the adoption of the European Parliament's Written Declaration on Hepatitis C and the European Centre for Disease Prevention and Control's (ECDC) decision to include viral hepatitis in its annual work plan as of 2008, as well as a compilation of expert recommendations on screening, which were endorsed by the European Association for the Study of the Liver (EASL).

For a sustainable change in the perception of liver diseases by the public and decision-makers in public health and a subsequent improvement of the situation for patients and specialists, it will be important for both to move beyond the immediate doctor–patient relationship and address jointly a wider audience. Essential in this context is the link to cancer. Policymakers have to know that by taking preventative measures (primary and secondary) against liver disease they prevent liver cancer, one of the few cancers on the rise in Europe.

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1. Introduction

Hepatologists and liver patients meet fairly late in life. This is frustrating for the former and potentially fatal for the latter, who often learn of their condition only after decades. If they met earlier, many liver diseases could be controlled or even cured. This might be a simple truth for insiders. However, changing this situation is rather complex. Part of the problem is the nature of the liver: whilst other organs such as the stomach, heart or kidneys cause the patient to feel pain very soon when they are sick, the liver suffers in silence. That “modest” an organ is the liver that, in 2006, the German weekly newspaper *Die Zeit* even failed to include it in an article which was meant to describe the most important organs in the human body. Whereas we cannot change this medical truth, we can contribute to raising the public's awareness of liver diseases and their devastating consequences when diagnosed too

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Abbreviations: ELPA, European Liver Patients' Association; ECDC, European Centre for Disease Prevention and Control; EASL, European Association for the Study of the Liver; WHO, World Health Organisation; EHRN, Eurasian Harm Reduction Network, CEE-RHN, Central and Eastern European Harm Reduction Network; EU, European Union; HIV/AIDS, human immunodeficiency virus/acquired immune deficiency syndrome; MRSA, methicillin-resistant *Staphylococcus aureus*; MEP, Member of European Parliament; InVS, Institut de Veille Sanitaire; EMCDDA, European Monitoring Centre for Drugs and Drug Addiction; MAC, MEPs against Cancer; HCV, hepatitis C virus; HBV, hepatitis B virus.

late. This is what the European Liver Patients' Association (ELPA) strives to do.

2. ELPA – Origin, aims, structure

With relatively little attention currently being paid both to liver-related illnesses and the silent progression of liver disease, it is only natural that patient groups in the field are low in number compared to other disease areas. That is not to say that they are ineffective. On the contrary, throughout Europe self-help groups are doing a fantastic job in providing information and counselling to those diagnosed, supporting them and their families throughout the therapy and facilitating contacts with doctors. In addition, they are trying to raise awareness amongst the public, and this is the part of their job they are struggling with: the public – this undefined, hard to grasp, heterogeneous mass – seems oblivious to the threat hepatitis is posing.

This is why national liver patients' associations across Europe have joined forces to form ELPA, which was formally launched on 14 April 2005 during the EASL annual conference in Paris. Today, ELPA counts 21 members in 17 countries. These cover all corners of Europe: Portugal and Spain in the West, the UK and Sweden in the North, France, Germany and Poland in the Middle, Italy in the South, Croatia, Bulgaria and Romania in the East. It even includes organisations in the wider Mediterranean area such as Egypt and an associate member in Turkey.

Quoting from ELPA's mandate, we aim "to promote the interests of people with liver disease and in particular: to highlight the size of the problem; to promote awareness and prevention; to address the low profile of liver disease [...]; to share experience of successful initiatives; to work with professional bodies such as EASL and with the European Union to ensure that treatment and care are harmonised across Europe to the highest standards". Whilst we mention "liver disease", ELPA's current focus (for capacity reasons) lies almost exclusively on viral hepatitis B and C as they are the most frequent forms of liver disease. Most ELPA members however, provide services also for other liver diseases, such as haemochromatosis, Wilson's disease or auto-immune liver diseases.

Before turning to ELPA's activities to raise the level of public awareness, let me first briefly recapitulate why ignorance about hepatitis is dangerous not only for those who suffer from it, but also for the wider public. Secondly, I would like to illustrate the lack of knowledge and concrete policy action to effectively fight the disease.

3. Why ignorance about hepatitis is dangerous

The long-term consequences of late diagnosis – liver cirrhosis and liver cancer – can be severe and potentially

fatal. Cases (75–85%) of primary liver cancer are attributable to chronic infections with hepatitis B or hepatitis C [1]. Liver cancer is the third highest cause of cancer deaths worldwide, and in Europe, liver cancer-related deaths have increased significantly over the past two decades (Fig. 1) [2].

What is more, the peak in the number of patients suffering from cirrhosis and cancer, or of those waiting for a life-saving liver transplant, has not yet been reached, as many of the chronically infected have not yet reached the advanced stages of the disease. This is why the WHO has compared viral hepatitis to a "viral time bomb" [3].

However, despite the serious health risks associated with it, viral hepatitis is not on the radar screen of decision-makers, and the public is generally not aware of this threat. This lack of political will to introduce strong measures to prevent the spread of hepatitis and further the identification of hepatitis patients not only ignores the human suffering caused by the disease, but also disregards the considerable socio-economic burden placed on national health systems and the economy at large.

4. Hepatitis – What is known and done

The majority of hepatitis sufferers in Europe are unaware of their condition. In the case of hepatitis C, estimates by the EHRN (formerly the CEERHN) suggest that up to 90% of hepatitis C carriers do not know that they are infected [4].

This is confirmed by two surveys which ELPA has conducted amongst its members and fellow hepatitis

	1980-1984	1990-1994	2000-2004
Portugal	0.9	2.2	2.7
Italy	5.6	8.2	6.7
France	3.6	6.9	6.8
Austria	3.5	3.7	4.25
Germany	1.7	2.5	2.85

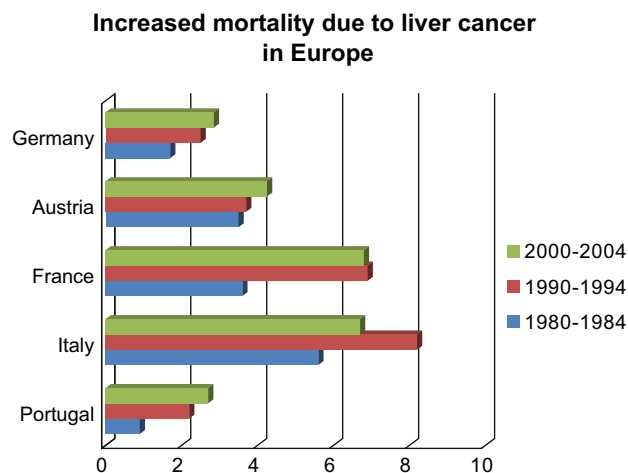


Fig. 1. Increasing mortality due to liver cancer in Europe (1980–2004).

patients. Throughout Europe, an average of only 21.5% knew of hepatitis at the time of their infection (23% for hepatitis B and 20% for hepatitis C), and only 27% knew that they were at risk (both for hepatitis B and C).

Whilst reimbursement and access to treatment is not an issue for a majority of ELPA's members, the insufficient awareness of hepatitis amongst policymakers, healthcare professionals and the wider public is regarded as a serious problem: 59% of patient organisations have noticed a lack of any incentives for healthcare professionals to conduct hepatitis screening tests. Furthermore, 75% of ELPA's members rate the political commitment with regard to hepatitis as either low or very low (Fig. 2). Lastly, ELPA members noted that only a handful of countries or regions in the EU, such as Spain, France, Croatia, and the United Kingdom, have developed a plan to fight hepatitis, including France and Scotland, whilst in the vast majority of the countries there has never been a public hepatitis awareness campaign (Fig. 2) [5].

5. ELPA's EU policy campaign

Since ELPA's members encountered difficulties in getting the attention of national policymakers for the concerns of hepatitis patients, ELPA has turned to the EU for political guidance on how to further the identification of undiagnosed hepatitis patients. Although the EU has only little direct competence in public health, it can drive change in the areas of disease prevention, cross-border health and the promotion of best practice, by issuing guidelines and recommendations.

Whilst the EU has adopted strategies on HIV/AIDS, MRSA, tuberculosis and malaria, European hepatitis-related activities remain scattered and lack momentum. Having analysed actions that address hepatitis, we can say that the EU is focused almost exclusively on primary

prevention; the prevention of contracting the virus. The importance of primary prevention was highlighted in the 2006 European Parliament resolution on "protecting European healthcare workers from blood-borne infections due to needle stick injuries" [6]. ELPA is of course very supportive of these efforts. However, we feel that the EU does not give equal attention to the great number of undiagnosed hepatitis carriers who receive little or no support as soon as they have been diagnosed. Only one EU initiative so far sought to promote case-finding, the EU Council Recommendation on drug-related harm [7], which advises Member States on how to identify hepatitis-infected drug users. Again, ELPA is supportive of this EU legislation. However, the EU must not neglect that there are other risk groups besides drug users. In ELPA's opinion, these have to be specifically addressed as well with a view to identifying hepatitis carriers before it is too late.

Targeted screening or case-finding, as it is practiced in regions like Scotland or other EU Member States such as France, has proven effective in substantially increasing the number of identified hepatitis patients and enabling them to receive appropriate treatment.

Unfortunately, such examples of good practice are confined to a fairly limited territory. At a time when thankfully Europe is becoming more and more borderless and people have the right to travel and settle wherever it pleases them, these efforts are not enough. As with all communicable diseases, viral hepatitis does not know any borders, and efforts in one European country can be undermined by less consistent efforts in a neighbouring state. There is hence, a clear need for greater cross-border coordination and an EU-wide approach on how to implement screening strategies and target these to risk groups across Europe.

A Council Recommendation on hepatitis B and C screening of risk groups would be a powerful tool in this context. Although not legally binding, such a recommendation is signed by all 27 health ministers of the European Union and hence represents an important political commitment. Furthermore, Member States would receive guidance on how to improve their efforts in detecting and treating unidentified hepatitis patients. At the same time, national patient organisations would be able to refer to this document, should policymakers fail to abide by their commitments.

5.1. The European Parliament

So far, one of the three EU Institutions has fullheartedly supported ELPA's campaign from the very beginning. Briefed by ELPA and its members, the European Parliament adopted a Written Declaration on hepatitis C by a comfortable majority of 470 votes out of 736 in March 2007, as one of the first disease-specific Written Declarations. Since then, the European

Overall, how would you rate the level of political commitment in your country to the fight against hepatitis B and C?

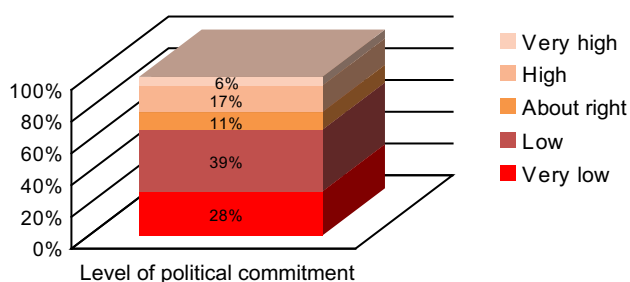


Fig. 2. ELPA Member Survey 2008 – ELPA member organisations rate the level of political commitment to the fight against viral hepatitis in their country.

Parliament hosted high-level events on the occasion of World Hepatitis (Awareness) Day in 2007 and 2008. (The World Hepatitis Day 2009 unfortunately took place during the European Parliament election campaign, so no event took place.) Furthermore Dr. Jolanta Dičkutė (MEP), together with ELPA, assembled experts for an informal meeting in November 2008 to work on a set of concrete recommendations for the enhanced detection of hepatitis B and C amongst risk groups. The recommendations, which were finalised in February 2009, have been endorsed by EASL, officials from the French InVS, the French Ministry for Health, the Scottish Health Protection Agency, the EMCDDA as well as leading Epidemiologists and Virologists [8]. In particular, the document includes a detailed list of all defined hepatitis B and C risk groups, for which targeted screening would be advisable (Table 1) – indeed the first Europe-wide guideline to provide such a comprehensive list. In addition, the experts argued in favour of the inclusion of liver enzyme tests (GPT tests) in preventative medical check-ups. These recommendations were presented to European policymakers at an event on 2 March 2009 in the European Parliament, which benefited from the kind support of Mr. Alojz Peterle MEP, former Slovenian Prime Minister and Chairman of the MAC group.

5.2. The European Commission

As far as the European Commission and the Council, are concerned, the response has been mixed so far. Regarding the Council Recommendation on targeted screening of viral hepatitis, it would be the European Commission's job to draft such a document before it can be adopted by the Council of Ministers. Whilst the European Commission is therefore in the driving seat, it seeks to obtain reliable and comparable data first before taking any decision. ELPA understands this concern to some extent, and therefore lobbied the EU agency in charge of disease-specific data collection, the ECDC, in autumn 2007. We were successful: at its annual meeting in December 2007, the ECDC's Management Board decided to include viral hepatitis – B and C – in its priorities for 2008. Subsequently, the ECDC declared its intention to develop a protocol for enhanced surveillance on hepatitis B and C in the EU. The agency furthermore announced that it would work on a report on the health of migrants, which would include a study on infections with hepatitis B and C. The two reports were expected to be published in summer 2009. However, it now seems that there is a significant delay in the agency's work on hepatitis due to a lack of suitable staff. This is extremely disappointing

Table 1

Definition of risk groups, as included in the *Expert Recommendations for the Promotion of case-finding for viral hepatitis B and C, including targeted screening measures for risk groups*.

The definition of high risk groups is an essential tool in designing targeted screening programmes for viral hepatitis	
High risk groups for hepatitis B	High risk groups for hepatitis C
<ul style="list-style-type: none"> • Persons with elevated liver enzymes and/or clinical sign of hepatitis • Patients with liver cirrhosis or fibrosis • Patients with hepatocellular carcinoma • People who share or have ever shared needles (injecting drug users) • People with long-term imprisonment history • People who are undergoing or have undertaken hemodialysis • Men who have sex with men or heterosexual persons with multiple sex partners • People with HIV or HCV infection • Families and household members or sexual partners of persons infected with HBV • Patients and staff in psychiatric institutions or residents of welfare institutions for mentally disabled persons • Pregnant women and newborns of HBV-infected mothers • Recipients of organ transplants and blood products • Blood and organ donors • Patients before or during immunosuppressive treatment or chemotherapy • Migrants from countries with high prevalence of hepatitis B • Unvaccinated healthcare workers and public safety workers who undertake exposure-prone procedures 	<ul style="list-style-type: none"> • Persons with elevated liver enzymes and/or symptoms of hepatitis • Patients with liver cirrhosis or fibrosis • People who share or have ever shared needles (injecting drug users) • People with long-term imprisonment history • People who are undergoing or have undertaken hemodialysis • People who have received repeated percutaneous injections • People who have had invasive medical and paramedical or dental work in countries with high prevalence or poor sterilisation procedures, such as use of multidose vials • People who received blood transfusions or other blood derived products outside the EU or before 1992 in the EU • People who received organs and tissues transplants outside the EU or before 1992 in the EU • Haemophiliacs who received concentrated coagulation factors before 1987 • People with HIV infection • People who have used intra-nasal cocaine • People with body piercings if being performed in non hygienic environments • Children of HCV-infected mothers • Healthcare workers and public safety workers who undertake exposure-prone procedures

for ELPA. As much as we understand the need for good data, it should not become an excuse for political inertia and not lead to a delay in taking the necessary policy measures.

Whilst the European Commission has not yet formulated an EU strategy against hepatitis, it has put forward hepatitis as one of its priorities in this year's call for proposals under the Public Health Programme. ELPA is very grateful for this opportunity. Together with our members we have submitted a proposal to promote the exchange of best practice amongst patient groups across Europe and we very much hope that our application for funding will be successful.

Another area of EU public health which requires the attention of liver patients is cancer. The European Commission has brought together a European Partnership on Action against Cancer, which will be formally launched on 29 September 2009. Apart from contributing to a future EU cancer strategy, this partnership will make suggestions as to how to revise the Council Recommendation on Cancer Screening from 2003.

To date this Council Recommendation only comprises three types of cancer: breast, cervical and colorectal. In light of the significant rise that liver cancer has experienced in the last decades – recent figures from the UK suggest that this particular cancer has quadrupled in the past 30 years [9,10] – this focus seems outdated and incomplete. In a preparatory meeting of the cancer partnership in March this year, ELPA – with the support of EASL – argued accordingly for an inclusion of liver cancer in the framework of this revised legislation. Needless to say, we would be delighted if the Council and Commission were to take possession of our argumentation and we very much hope to be able to contribute when preventative measures against liver cancer are being defined. Apart from awareness-raising of alcohol-abuse and obesity, actions to promote the identification and – where appropriate – treatment of hepatitis carriers should most definitely be included.

5.3. Member States

Although Member States have not yet had an opportunity to comment on a future Council Recommendation, ELPA members have successfully used the EU momentum to get in touch with national policymakers. Examples of their work include the recent testing for hepatitis in the Sejm, the Polish Parliament, on the occasion of this year's World Hepatitis Day (organised by our Polish Member Prometeusz with the support of former Prime Minister and current President of the European Parliament, Professor Jerzy Buzek); talks of our Italian member EpaC with the Italian GP association to promote the EASL/ELPA

expert recommendations on hepatitis; and discussions with parliamentarians in Germany.

6. Conclusion

This is – along general lines – a summary of ELPA's activities in the past three years to promote awareness of hepatitis amongst policymakers and specifically highlight the importance of early diagnosis for the sake of European patients and health systems alike. Our learning curve has certainly been a steep one, and sometimes the paths used may have seemed a bit longwinded from an outsider's point of view. We nonetheless firmly believe that we are on the right track.

One thing, however, is clear: we could never have done it without the unfailing support of the EASL Governing Board who has helped us from the very beginning of our activity. ELPA is very grateful to former Secretary General Professor Jean-Michel Pawlotsky and his successor Dr. Heiner Wedemeyer. Just to give you an example: Right before this year's EASL annual meeting, at the European Parliament event in March 2009, Dr. Wedemeyer gave an impressive presentation illustrating in particular the link between hepatitis and liver cancer. His presentation contributed to this topic being taken on board by key Parliamentarians in the inter-institutional health dialogue in September this year.

Another case in point for our very constructive cooperation is represented by the ELPA workshop at the annual EASL meeting – for ELPA's members it is extremely important to be able to showcase and discuss best case examples in this framework – and we hope to continue in this way.

A doctor-patient relationship based on trust is therefore not only the key to a successful therapy but close co-operation between doctors and patients is also essential when seeking to improve public health. I would therefore like to encourage of all of you who read this article to become active on this front. Discuss with your local patient group how you can jointly approach your local MP, the health minister, a public sick fund or an association of general practitioners.

Only if we all step out of the specialist box and approach those who are responsible for taking public health decisions can we ensure that hepatologists and liver patients meet earlier in life.

For the future, we therefore want to continue our policy campaign on hepatitis screening for risk groups – both at EU and national level, with a particular focus on central and Eastern Europe where – as we all know – prevalence rates are particularly high. At the same time, it will be important to also direct policymakers' attention to other liver diseases, too.

Hepatitis is just the beginning.

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