



Report

ELPA Symposium

“Best practice in raising awareness in
migrant populations“,

Copenhagen, 25th April 2009



Hepatitis B and C: Raising awareness in migrant populations

Report from the ELPA symposium in Copenhagen, 2009

COPENHAGEN - More than 500 million people around the world are currently infected with hepatitis B or C. The HBV/HCV-related deaths are high and increasing: Approximately one million people a year die due liver-cirrhosis or liver cancer caused by hepatitis B and C. Both types of viral hepatitis can affect everyone regardless of social belonging, age, gender or ethnicity. Recent studies showed that the incidence of HCC caused by hepatitis C is rising dramatically: Decades after the infection many patients are now diagnosed for the first time with chronic hepatitis. If they had been identified earlier, many of them could have been treated successfully. Therefore it is very important to increase awareness of the disease to prevent hepatitis and to reach patients before they develop late-stage liver disease or liver cancer.

Many people with hepatitis are not aware of their infection. Hepatitis patients in general are

vulnerable to health and social consequences, all the more if they are migrants: Communication problems - e.g. less education or language barriers - with doctors and healthcare-providers complicate the attempt to offer appropriate treatments. In addition, it is often also taboo to talk about hepatitis.

Respect and understanding

To establish successful hepatitis-campaigns in migrant-populations is much more delicate than to raise awareness in non-migrant communities - which is already very difficult. „It is vital to respect cultural differences and to take this into account when reaching out for migrant communities“, said Nadine Piorkowsky, President of the „European Liver Patient Association“ which held an international symposium* during the last annual meeting of the „European Association for the Study of The Liver “ (EASL) in Copenhagen. The aim of the



From left to right: Dr. Manuel Carballo, Achim Kautz, Nadine Piorkowsky, Prof. Claus Niederau, Dr. Marc Lütgehetmann, Greet Boland

meeting, which was organized by Achim Kautz, CEO of the Deutsche Leberhilfe e.V., was to share experience in raising hepatitis-awareness in migrant populations who live in different European countries.

Migration around the world

The dimension of migration was illustrated by Dr. Manuel Carballo from the WHO collaborating International Centre for Migration, Health and Development (ICMH), Geneva. More people are moving faster and over wider distances than before: Worldwide there are 50 million refugees, 500 million migrants and a huge count of irregular migrants. And there are more than 700 million travels by tourists, which can be hazardous concerning hepatitis-risks during medical procedures, sex, tattooing or others.

The challenge will be to find out how and when to reach migrants, to treat them if necessary and to care for follow-up. „It is very important to create the evidence base for policy and program“, said Carballo, „and to implement advocacy and planning.“

The hidden epidemic

An estimated 170 million people are chronically infected with HCV globally, most of them are living in developing countries. In the UK, a lot of

Bangladeshi and elder Pakistani are HCV positive. One main focus in screening hepatitis C are persons with intravenous drug abuse (IDU) – so a lot of people, including immigrants without IDU, are not aware that they could have been at risk for HCV, said Professor Graham Foster, London. He found out that immigrants often do not use common information sources like local newspapers, so it is difficult to reach them. Foster received support by the „DH/Big Lottery“, which funded a hepatitis study in South Asians living in the UK. With the consent of religious communities, there have been screening-sessions by volunteers who screened with oral swabs. In total, 3847 people were

screened, the HCV-prevalence ranged from 0 – 3,5 % through different age groups with a higher prevalence in women at the age of 30 till above 70 years.

„This meeting is that important because we must begin to draw attention to the hidden hepatitis C epidemic. Our experience in London showed that the most important thing is to really engage with the community, make sure that you understand their problems and then to translate their problems and solve them for their community. It is important to work with tailored solutions to be successful because each community has its own problems and difficulties“ said Graham Foster.



Dr. Graham Foster reports from his screening project in London

Hepatitis B: a big issue

40 % of the world population were actually affected or have been infected with Hepatitis B. 350 million chronic carriers worldwide are at a high risk for liver cancer (HCC), which is the third most frequent cause of cancer-related death. Only 20 % of the chronic HBV infected patients in Europe are diagnosed and less than 15% of those get appropriate treatment, explained Dr. Marc Lütgehemann, Hamburg. Data showed that about 66 – 81 % of the chronically HBV infected patients in Germany had a migratory background (Niederau C. 2007, Hüppe D. 20007, Meyer F. 2007): Germany represents a migrant country. A survey of HBV-patients conducted at the Department of Medicine, University Hamburg, showed only one third of them are female. The knowledge of HBV-patients about routes of transmission, the progression of the disease and vaccination are mostly poor (34%) to moderate (51%). This is influenced by gender, migration background, education and language. German language skills are correlated with a better knowledge of HBV and vaccination. One Part of the HBV high-risk population are sex-workers: the „Epidemiological Bulletin“ of the Robert-Koch-Institut reported one study in 2008, which showed that 90 % of migrant sexual workers have been infected with HBV, and only 6% have sufficient HBV-vaccination.

More than 35 million migrants live in Western Europe, who often come from countries with a high HBV prevalence. Migrants from endemic regions are 5 to 90 times more likely to be affected by HBV than host populations, explained Prof. Claus Niederau MD, Oberhausen, of the Deutsche Leberhilfe e.V.. An analysis of patient data from Niederau's hospital showed that 35 % of the HBV-patients are Turkish, 33 % come from other countries and 32 % were born in Germany. Consequently, the German guidelines for the diagnosis of chronic hepatitis B advise to determine HBsAg in all persons who are born in countries with a high HBV prevalence.

Two countries, one aim

To reach hepatitis B patients in time, Deutsche Leberhilfe e.V. established a project with the Turkish Liver Foundation and the well-known

Turkish gastroenterologist Prof. Muzaffer Gürakar. Together they contacted the Turkish Minister of Religious Affairs, who convinced the German imam representative to alert the Muslim community in Germany about hepatitis B vaccination, diagnosis and treatment. German Muslim association (DITIB) and Deutsche Leberhilfe e.V. prepared an awareness plan, including a campaign to inform Turkish doctors in areas with a high rate of Turkish migrants. The awareness concept included information about HBV-vaccination, diagnosis and treatment, as well as brochures and flyers in Turkish. On the occasion of World Hepatitis Day on 19th May 2008, the head imam joined the press conference as a speaker. This event attracted attention by Turkish newspapers and other media. Only four days later, imams in 900 German mosques spoke to their communities about hepatitis B, and helped to raise awareness.

Many hepatitis awareness projects can be found in the Netherlands as reported by Greet Boland, of the National Hepatitis Centrum, Utrecht. There have been campaigns such as 'China aan de Maas' to raise Hepatitis B awareness in Chinese people from Rotterdam, which used a website, buses, media, Chinese doctors and the Chinese church.

Boland said that it was very important to consider „cultural tailoring“ to identify individual and social-cultural environmental determinants of participation in hepatitis B testing and vaccination in the Turkish community in the Netherlands. Another way to raise awareness was a hepatitis-C-risk-assessment via Internet (www.heptest.nl) and a subsequent lab-testing for free in Amsterdam and Limburg. Boland concluded: firstly, campaigns work best when people with the same ethnic origin are involved, and secondly, to focus on risk groups increases the success. And last but not least, general practitioners should be involved – their education is essential. “We have to realize that communication with migrants has its own rules: we can be much more successful if we respect their cultural characteristics by creating individual campaigns and programs”, summarized Achim Kautz, “moreover we should keep in mind that a lot of immigrants have problems due to their status as foreign persons. We should act carefully and avoid to add more problems or stigma because of hepatitis.”

Simone Widhalm, Duesseldorf

Raising awareness in migrant populations:

Do's and Don'ts

Do:

- Communicate on the same level, and cooperate as partners
- Use internal communication channels (understand how communications really happen within the particular community): for example, consider using print, online, radio/TV, cultural clubs, word-of-mouth / personal communication
- Choose the right style and sophistication of language – the simpler the better – balancing rational facts and emotive content
- Choose the right advocates – people who have credibility for the specific group
- Set the table before you start cooking: make sure that the consequences of the communication can be satisfied.
Example: If you communicate “get tested”
 - *it is essential to get buy in of physicians to such a campaign in order to provide tests for requesting individuals*
 - *Make sure that the target audience has appropriate access to medical care, drugs etc.*
- Maintain a regular / continuousness stream of communication (to maintain credibility)
- Explore multilateral approaches and develop networks in order to execute joint actions
- Use existing networks (such as ELPA, World Hepatitis Alliance, EASL, WHO), and publish details of your own contact persons
- Involve native speakers/members of the particular community as consultants (to gain insights and advice) and as additional communicators

Don't:

- Don't communicate or cooperate „top-down“
- Don't do anything that could be considered discriminatory, or that could lead to social exclusion (this will vary across countries and communities)
- Don't use Mass Media without careful planning and personal contact with journalists (no control, uncontrollable dynamics, improper communication) assess the risk of inappropriate communication
- Avoid promises which can not be fulfilled (re access to medical care, reimbursement of drugs etc.)



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