SOCIAL IMPACT OF HCV
Rui Tato Marinho

Provided as a service to patients and medicine, organised and funded by Gilead Sciences Europe Ltd. in partnership with ELPA who have developed the content and themes for the meeting. The final content of the programme is at the discretion of the International Taskforce.
OVERVIEW

• Hepatitis C – physical, mental, social
• Social impact
  – Stigma and discrimination
  – Prisons
  – Homelessness
  – Unemployment
  – Loss of productivity
• Solutions
HEP C: BACKGROUND

• Worldwide prevalence: 3%¹
• Average age: 40-50 years old
• ‘Core business’: liver cirrhosis

Hepatitis C, Hepatitis B, alcohol, obesity

CIRCLE OF LIVER DISEASE

- Acute hepatitis
- Chronic hepatitis
- Liver cirrhosis
- Decompensated liver cirrhosis
- Hepatocellular carcinoma
- Transplant
- Palliative care
- Death

Authors image
FOUR KEY ‘C’ IDEAS

- Cirrhosis
- Risk of Cancer
- Risk of death (Cemetery)
- But Cure
SILENT DISEASE

- Acute hepatitis
- Chronic hepatitis
- Liver cirrhosis
- Hepatocellular carcinoma
CHRONIC HCV INFECTION IS CURABLE

LANDMARKS – CURE HEPATITIS C (GENOTYPE 1):

TYPES OF HCV THERAPY

- Triple
- Double
- Oral
MENTAL IMPACT

How to Break Bad News
A Guide for Health Care Professionals

ROBERT BUCKMAN, M.D.
with contributions by Yvonne Kason, M.D.
A comparison between Hep C and other stressful life events and chronic diseases

- The results of the study by Castera et al. showed the psychological and emotional burden that a diagnosis of Chronic Hepatitis C (CHC) represents, even in the absence of significant liver disease.

- In order to reduce negative effects, these should be taken into account when announcing a diagnosis of CHC.
PSYCHOLOGICAL IMPACT OF HEPATITIS C

- The VAS score for divorce and death of a loved one was higher than a CHC diagnosis.
- Similarly, the VAS score for cancer or AIDS was higher than CHC.


VAS = Visual analogue scale
A study to evaluate whether individuals consider their HCV infection to be a potentially traumatic experience

- Approximately 38.6% of patients considered Hepatitis C to be a traumatic experience.
- Of these, 60.7% had a PTSD diagnosis.

HCV is frequently a traumatic experience and it is strongly associated with PTSD diagnosis.


PTSD = Post traumatic stress disorder
A European expert consensus statement organised by ELPA

- Aim: develop expert recommendations for the management of mental health problems in HCV infected patients

QUALITY OF LIFE
An overview of the main organ systems affected by and potential adverse events associated with combination Antiviral (AV) therapy

**MANAGEMENT OF THE ADVERSE EFFECTS OF COMBINATION ANTIVIRAL THERAPY FOR HEPATITIS C**

Constitutional events
(Influenza-like symptoms and fatigue)

Infectious diseases
(e.g. oral cavity infections, respiratory infections and skin infections)

Autoimmune disorders
(endocrine [hypothyroidism/hyperthyroidism] and rheumatologic conditions)

Dermatologic disorders
(e.g. alopecia and dermatitis)

Cardiovascular events
(myocardial ischemia and cardiomyopathy)

Gastrointestinal events
(e.g. nausea and diarrhea)

Neuropsychiatric events
(Depression, manic conditions and cognitive dysfunction)

Ophthalmologic diseases
(e.g. retinal abnormalities and loss of visual acuity)

Pulmonary events
(e.g. cough and dyspnea)

Hematologic disorders
(Anemia, neutropenia and cytopenia)

HEPATITIS C INFECTION, ANTIVIRAL TREATMENT & MENTAL HEALTH

A European expert consensus statement organised by ELPA

- Prevalence of peg-interferon alpha associated side effects

<table>
<thead>
<tr>
<th>Side effect</th>
<th>Prevalence (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>39 – 80</td>
</tr>
<tr>
<td>Sleep disturbances</td>
<td>18 – 45</td>
</tr>
<tr>
<td>Irritability</td>
<td>16 – 50</td>
</tr>
<tr>
<td>Anxiety</td>
<td>11 – 45</td>
</tr>
<tr>
<td>Cognitive disturbances</td>
<td>2 – 30</td>
</tr>
<tr>
<td>Mania</td>
<td>0 – 3.2</td>
</tr>
<tr>
<td>Psychosis</td>
<td>0 – 0.6</td>
</tr>
<tr>
<td>Suicidal thoughts / ideation</td>
<td>3.5 – 10</td>
</tr>
<tr>
<td>Suicide / suicide attempts</td>
<td>0 – 0.02</td>
</tr>
</tbody>
</table>

A national survey of Portuguese hospitals in 2001

Probable route of infection

- Drug user i.v. (81%)
- Transfusion
- Sexual contact
- Other
- Contact with HCV patient
- Perinatal transmission

Identifiable: 461 (81%)

A lot of PWID are now very active and productive for society.
OVERVIEW

- Hepatitis C – physical, mental, social
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  - Stigma and discrimination
  - Prisons
  - Homelessness
  - Unemployment
  - Loss of productivity
- Solutions
STIGMA / DISCRIMINATION
• Self – auto-stigma
• Family
• Conjugal
• Workplace (professional)
• Healthcare setting (not so rare)

• Confidentiality
STIGMA AND DISCRIMINATION
IN PUBLICATIONS AND MEDIA

Neuropsychiatric and Psychosocial Issues of Patients With Hepatitis C Infection: A Selective Literature Review
Amirhossein Modabbernia¹,², Hossein Poustchi³, Reza Malekzadeh¹

“They Treated Me Like a Leper”
Stigmatization and the Quality of Life of Patients with Hepatitis C
Susan Zickmund, PhD, Evelyn Y. Ho, MA, Masahiro Masuda, PhD, Laura Ippolito, BA, Douglas R. LaBrecque, MD
Stigmatization is defined as attitudes expressed by a dominant group which views a collection of others as socially unacceptable.

- It can affect the self-esteem and QoL of the affected individuals.
- Certain categories of patients have been ostracized throughout history, as exemplified by individuals infected with leprosy or HIV.
- In the medical environment, stigmatization may cause difference in delivery or even frank denial of treatment, both of which can result in severe adverse effects for the patient.
- Stigmatization codes: We operationally defined stigmatization as being negatively judged by others and as a result of the patient’s HCV infection.

“*They treated me like a leper*”: Stigmatization and the QoL of patients with Hepatitis C

In a concept of analysis, stigma in the context of HCV was defined as a subjective and variable, perceived (usually) negative phenomenon. From this point of view, stigma has interrelated intrapersonal, interpersonal and structural dimensions. As a distinctive aspect of the HCV-related stigma in its relation to injection drug users (IDU), stigma negatively affects the HR-QoL, mental health and social life of the patients, and leads to difficulties with receiving or accepting treatment. In different series from 35% to more than 85% of the patients with HCV were reported to experience stigma. Stigma can occur as a result of discrimination. In an Australian study on over 500 patients with HCV, 65% reported discrimination which most commonly had occurred in the healthcare setting.
HOW TO COMMUNICATE WITH HCV PATIENTS

Tender loving care
BAD NEWS

- Physical
- Mental – existential crisis, a real trauma
- Social
Inform, talk, be silent

- Cure
- Prepare for no cure – always hope
- QoL (positive psychology) – family, friends (some), good food, sport, music, travel, culture, sleep, social life etc.
BAD NEWS CONTINUED…

‘Moment’ of the News – Golden Hour

• Cure

• Infect others?

• Prepare for no cure – always hope

• Quality of life (positive psychology) – family, friends (some), good food, sport, music, travel, culture, sleep, socialise, etc

PLAN

BREAKING BAD NEWS

buckman’s 6-step guide

S.P.I.K.E.S

• Setting, listening Skills
• Patient’s Perception
• Invite patient to share Information
• Knowledge transmission
• Explore Emotions and Empathise
• Summarise and Strategize

1. Privacy, no physical barrier, quiet place
2. Shake hand, name of patient
3. Sit down, 2–3 m, be quiet
4. Other people – family, but first the family
5. Turn off mobile phone, no computer
6. Visual contact 50–60% of time, same level
7. Silence, give time, stop, ask
8. Repeat words, no technical terms
9. Smile, never lie, honest
10. 18–30 mins

Non-verbal communication is often more important than verbal communication

**HEPATITIS C, STIGMA AND CURE**

### Benefits of cure of Hepatitis C

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Causes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative HCV RNA (viral load) for life, in more than 99% of cases</td>
<td>Changing of ultrasound finding (contours can become regular, reduce of diameter of portal vein in case of portal hypertension)</td>
</tr>
<tr>
<td>Negative HCV RNS in the liver</td>
<td>Disappearance of the lymphnodes near the liver</td>
</tr>
<tr>
<td>HCV RNA negativation in PBMC</td>
<td>Decrease of the values for Elastography (Fibroscan®)</td>
</tr>
<tr>
<td>No detection of the genotype</td>
<td>Reducing to zero the risk of recurrence after liver transplantation (if necessary)</td>
</tr>
<tr>
<td>Sometimes, a few years later, the anti-HCV test can become negative, the so-called ‘seroreversion’</td>
<td>Normalization AST, ALT and GGT</td>
</tr>
<tr>
<td>Normalization AST, ALT and GGT</td>
<td>Disappearance of the risk of progression to liver cancer</td>
</tr>
<tr>
<td>Disappearance of the risk of perinatal transmission</td>
<td>Reducing the risk of decompensated liver disease (ascites, jaundice, rupture of oesophageal varices, encephalopathy)</td>
</tr>
<tr>
<td>Decrease in the insurance premium</td>
<td>Cure of associated conditions (porphyria cutanea tarda, polyneuropathy, urticaria, cryoglobulinemia, splenic lymphoma)</td>
</tr>
<tr>
<td>Improved quality of life (asthenia, fatigue, general well-being)</td>
<td>Reducing personal, family and social stigma</td>
</tr>
<tr>
<td>Reducing of the psychological impact (anxiety/depression)</td>
<td>The treatment is proved cost-effective</td>
</tr>
<tr>
<td>The treatment is proved cost-effective</td>
<td>Benefit to public health</td>
</tr>
<tr>
<td>Reduced risk of death from liver disease</td>
<td>Neurocognitive improvement</td>
</tr>
<tr>
<td>Cure of hepatitis C</td>
<td>Reduced risk of death from liver disease</td>
</tr>
</tbody>
</table>

**Reduced risk of death from liver disease**

**Neurocognitive improvement**

**Cure of hepatitis C**

SUSTAINED VIROLOGICAL RESPONSE AND CLINICAL OUTCOMES IN PATIENTS WITH CHC AND ADVANCED FIBROSIS

The benefits of cure are evident already at 1-2 years of follow-up. We should not wait a long time to treat patients with cirrhosis.

Patients with cirrhosis who responded had a low risk of evolution to HCC, the opposite of those who did not respond.
PRISONS
A call for an evidence-informed response

- Globally over 10 million people are held in prisons and other places of detention at any given time. PWID comprise 10-48% of male and 30-60% of female prisoners
- Only approximately 60 out of more than 10,000 prisons worldwide provide needle exchange
- HCV prevalence in the general population in Western Europe is 0.5%, and that it is 2.5% and 6% in Southern Europe and Eastern Europe
- HCV prevalence in inmates was approximately 30-40% (range: 2-58%)
**ODDS RATIO FOR HEPATITIS C IN PRISONS**

**Relative risk of being infected with HCV in prison**

<table>
<thead>
<tr>
<th>Study</th>
<th>Odds ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Babudieri et al(^5)</td>
<td>10.44 (7.59 to 14.36)</td>
</tr>
<tr>
<td>Utsumi et al(^6)</td>
<td>8.62 (4.26 to 17.41)</td>
</tr>
<tr>
<td>Anon et al(^3)</td>
<td>89.59 (50.42 to 159.19)</td>
</tr>
<tr>
<td>Ford et al(^3,24)</td>
<td>28.87 (15.70 to 53.10)</td>
</tr>
<tr>
<td>Christensen et al(^22)</td>
<td>62.88 (31.42 to 125.84)</td>
</tr>
<tr>
<td>Butler and colleagues (^{18, 19, 49})</td>
<td>19.06 (10.15 to 35.79)</td>
</tr>
<tr>
<td>Malliori et al(^3)</td>
<td>39.34 (22.10 to 70.02)</td>
</tr>
<tr>
<td>Saiz de la Hoya et al(^11)</td>
<td>144.20 (81.32 to 255.70)</td>
</tr>
<tr>
<td>Subtotal</td>
<td>33.38 (15.77 to 70.66)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study</th>
<th>Odds ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Macalino et al(^0)</td>
<td>27.85 (24.15 to 36.17)</td>
</tr>
<tr>
<td>Fox et al(^25)</td>
<td>17.24 (10.52 to 28.25)</td>
</tr>
<tr>
<td>Gates et al(^26)</td>
<td>15.38 (4.28 to 55.30)</td>
</tr>
<tr>
<td>Crofts et al(^5)</td>
<td>9.63 (8.17 to 11.35)</td>
</tr>
<tr>
<td>Butler and colleagues (^{18, 19, 49})</td>
<td>9.75 (5.25 to 18.11)</td>
</tr>
<tr>
<td>Hedouin and Gosset et al(^29)</td>
<td>23.70 (13.89 to 40.47)</td>
</tr>
<tr>
<td>Holsen et al(^29)</td>
<td>23.73 (5.97 to 94.32)</td>
</tr>
<tr>
<td>Subtotal</td>
<td>16.54 (10.11 to 27.05)</td>
</tr>
<tr>
<td>Overall</td>
<td>24.32 (15.74 to 37.58)</td>
</tr>
</tbody>
</table>
HOMELESS
A systematic review and meta-analysis

- 100 million people worldwide are homeless
- 43 eligible surveys with a total population of 59,736
- 12 studies for hepatitis C
- 3.9% to 36.2% for hepatitis C virus infection
- Heterogeneity in prevalence estimates for tuberculosis, hepatitis C virus, and HIV suggests the need for local surveys

2012 NICE guidelines recommend that people in prison and homeless should be screened simultaneously for tuberculosis, Hepatitis C virus and HIV

### Prevalence of tuberculosis, hepatitis C virus, and HIV in homeless people: a systematic review and meta-analysis

<table>
<thead>
<tr>
<th>Country</th>
<th>Study size</th>
<th>Prevalence ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Male</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colson et al, 2011</td>
<td>France 220</td>
<td>5.1 (2.7 – 9.5)</td>
</tr>
<tr>
<td>Beijer, 2007</td>
<td>Sweden 1757</td>
<td>19.3 (16.7 – 22.3)</td>
</tr>
<tr>
<td>Burström et al, 2007</td>
<td>Sweden 123</td>
<td>42.7 (30.4 – 60.0)</td>
</tr>
<tr>
<td>Sheriff et al, 2003</td>
<td>UK 90</td>
<td>48.9 (34.8 – 68.8)</td>
</tr>
<tr>
<td>Boyce et al, 2009</td>
<td>USA 17</td>
<td>4.1 (0.8 – 20.1)</td>
</tr>
<tr>
<td>Rosenblum et al, 2001</td>
<td>USA 94</td>
<td>17.6 (13.4 – 23.2)</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beijer, 2007</td>
<td>Sweden 528</td>
<td>31.6 (25.9 – 38.5)</td>
</tr>
<tr>
<td>Burström et al, 2007</td>
<td>Sweden 32</td>
<td>69.7 (43.4 – 111.9)</td>
</tr>
<tr>
<td>Sheriff et al, 2003</td>
<td>UK 8</td>
<td>50.2 (16.3 – 154.2)</td>
</tr>
<tr>
<td>Nyamathi et al, 2002</td>
<td>USA 884</td>
<td>11.2 (9.9 – 12.6)</td>
</tr>
<tr>
<td>Rosenblum et al, 2001</td>
<td>USA 45</td>
<td>13.6 (8.4 – 21.9)</td>
</tr>
<tr>
<td>Schwarz et al, 2008</td>
<td>USA 161</td>
<td>10.0 (7.4 – 13.7)</td>
</tr>
<tr>
<td>Boyce et al, 2009</td>
<td>USA 23</td>
<td>5.2 (1.5 -17.2)</td>
</tr>
<tr>
<td><strong>Mixed</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stein et al, 2011</td>
<td>USA 534</td>
<td>14.1 (12.3 – 16.1)</td>
</tr>
</tbody>
</table>

Decreased prevalence: 0.1 | 1 | 10 | 100

Increased prevalence: 1 | 10 | 100

HOMELESS IN LISBON, PORTUGAL

- Economic crisis
- Loss of housing and accommodation
- Poverty
- Social isolation

UNEMPLOYMENT
Unemployment rates (%) among 15–64 year olds, 2008–2012, selected European countries

WHO. Economic crisis, health systems and health in Europe: impact and implications for policy.
HEALTH CONSEQUENCES (PHYSICAL, MENTAL, SOCIAL)

- Alcohol, tobacco, drugs
- Frustration, aggression
- Antisocial behaviour
- Major depression
- Lower healthcare use
- Suicide
- Less medications consumption

Author's opinion.
“...unemployment has been seen as both the endemic and the most dangerous disease of modern society and economy”

Peter Drucker, 1976
86% of subjects infected with Hepatitis C had previously used injection drugs.

Of these subjects, 76.1% were unemployed.
LOSS OF PRODUCTIVITY
THE IMPACT OF HEPATITIS C ON WORK

2009 United States (US) National Health and Wellness Survey: Patients infected with Hepatitis C were compared to controls on labour force participation, productivity loss, and activity impairment after adjusting for demographics, health risk behaviours and comorbidities.

Results from both methodologies converged to indicate that HCV is associated with persistent indirect economic costs from a societal perspective.

Diagnosed with HCV
N = 695

Not diagnosed with HCV
N = 73,339

Patients with HCV were significantly less likely to be in the labor force than controls and reported significantly higher levels of absenteeism, presenteeism, overall work impairment and activity impairment.

Diagnosed with HCV and employed
N = 293

Not diagnosed with HCV and employed
N = 39,497

NHWS sample
N = 75,000

Excluded from analysis
N = 966

Diagnosed with HCV
N = 695

Not diagnosed with HCV
N = 695

Diagnosed with HCV and employed
N = 293

Not diagnosed with HCV and employed
N = 293

WORK PRODUCTIVITY AMONG TREATMENT-NAÏVE PATIENTS

Hepatitis C infected patients’, receiving combination AV therapy, employment status by treatment and study visit

One third of patients during triple therapy are out of work


*Week 36 data were not collected as part of ILLUMINATE. Data presented here for week 36 are from ADVANCE only.
WORK PRODUCTIVITY AMONG TREATMENT-NAÏVE PATIENTS

ILLUMINATE and ADVANCE studies: Hepatitis C infected patients’, receiving combination AV therapy, employment status by treatment and study visit

Percentage of employed patients reporting less productivity in work activity due to hepatitis or its treatment by visit

*Week 36 data were not collected as part of ILLUMINATE. Data presented here for week 36 are from ADVANCE only.

MULTI-DISCIPLINARY TEAMS

- Nurses
- Psychologists
- Psychiatrists
- Sociologists
- Patient organisations
- Patients
- Jurist / lawyers
- Advocacy groups
- Social workers
- Prisoners
- Homeless
- Drug addiction centres
HEPATITIS C EXISTS!

- D. Lavanchy, WHO, 2009
- Viral Hepatitis Prevention Board Meeting, Istanbul
OVERVIEW

• Hepatitis C – physical, mental, social
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  – Unemployment
  – Loss of productivity
• Solutions
SOLUTIONS

- Information, information, information! (general population, journalists, young people in schools, adolescents, politicians, health care workers, group of patients, prisoners, drug addicts etc.)
- National Plans of Viral Hepatitis
- Specialisation in health communication
- Golden hour - hour of communication of bad disease. Also communicate hope and positive things
- Teach how to communicate bad news
- Communicate data: burden of disease (HCV and liver disease), 7th cause of death in Europe, 7th in the world, 5th in UK
- Communicate the global picture of liver disease, an integrated picture. Liver disease is an infection, a disease, a cirrhosis, a cancer, a liver transplant etc.
THANK YOU