

The Malaysian Liver Registry: A Database of the Common Liver Diseases

S S Tan, I Merican

Department of Hepatology, Selayang Hospital, 68100 Batu Caves, Selangor, Malaysia

INTRODUCTION

The pattern of liver diseases varies regionally and geographically. The Liver Registry is a database of common diseases of the liver in Malaysia.

Digestive disorders was responsible for 3.2% of the total burden of disease in Malaysia in the year 2000. And cirrhosis of the liver was the most important cause of burden of illness among digestive disorders contributing to 60% of the total burden in this category¹.

This registry is a joint venture between the Ministry of Health Malaysia and the Malaysian Liver Foundation.

This database will be invaluable in the planning, operation, evaluation of health services and other policy management development for the Ministry of Health and other health care providers. Clinicians and other interested health care providers will also find this information useful for patient and public education.

MATERIALS AND METHODS

This is a retrospective and prospective observational study of the cases seen in a national tertiary referral liver unit (the Department Hepatology of Selayang Hospital). The registry is being developed in stages from 2003 and we have been collecting data on chronic hepatitis B, chronic hepatitis C and acute liver failure. Its activities, development and progress are directed by a steering committee consisting of the President and Council members of the Malaysian Liver Foundation. The registry is based in the foundation office and data are collected and entered from Selayang Hospital.

All patients with the above three liver diseases presenting to our outpatient and inpatient facilities are eligible. The initial reporting is done on a voluntary basis from attending clinicians. This is then followed up by a research assistant who collects detailed data from blood tests or other investigations from the patient's electronic medical records. The subsequent follow-up visit to this hospital is also captured for tracking of disease progression or treatment outcomes. Data is entered into a software application with in-built patient analysis and tracking systems. The data is cleaned and reviewed at regular intervals by the data manager or clinician.

RESULTS

There are 746 chronic hepatitis B(CHB), 164 chronic hepatitis C (CHC) and 71 acute liver failure cases registered.

Here we are reporting the initial data at presentation on chronic hepatitis B (n=746) and C (n=164) cases.

The demographic data for both CHB and CHC are reported in Table I.

On presentation 33.1% (n=247) of the CHB patients are asymptomatic. However 0.02% (n=18) patients already had hepatocellular carcinoma. Many of the patients also had features of liver decompensation at initial presentation, with 117 reports of jaundice, ascites (59), encephalopathy (6) and upper gastrointestinal bleed (22).

A positive family history was found in 239 CHB cases but an equally high number of patients (n=238) did not have family screening. The alanine aminotransaminase (ALT) levels on presentation in chronic hepatitis B patients are reported in Figure I.

For the CHC patients, 60.4% were asymptomatic on presentation. The presentation was for abnormal liver function test in 14.6% of cases and/or anti-HCV positive in 36%. The commonly reported possible risk factors include: previous blood or blood product transfusion in 46.3%; intravenous drug use in 22%; and high risk sexual behaviour in 17.1% while 17.7% of our CHC also were on hemodialysis. The ALT levels on presentation in chronic hepatitis C patients are reported in Figure II.

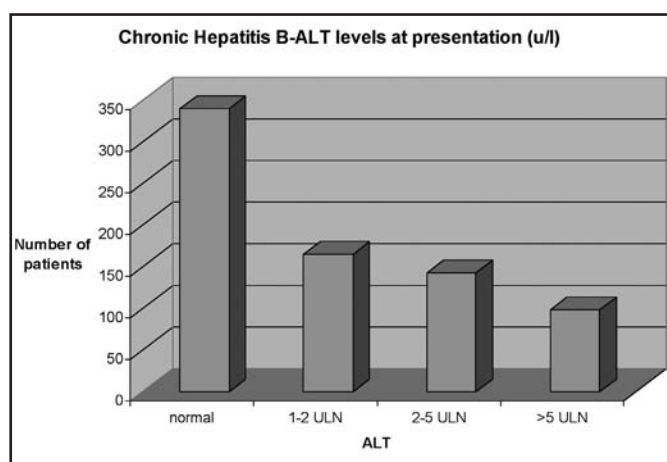
CONCLUSIONS

In this tertiary liver unit, our CHB and CHC patients are young and affect more males than females. We see both ends of the spectrum of severity of liver disease. More of the CHC patients were at the early asymptomatic stage compared to CHB patients. This could be due to greater awareness of risk factors for hepatitis C transmission and having screening performed. On the other hand a significant number of CHB patients presented with severe disease while there is an apparent lack of family screening measures despite this being the most common route of transmission in our region.

It is clear that public education about viral hepatitis, especially hepatitis B, is very much needed. The main

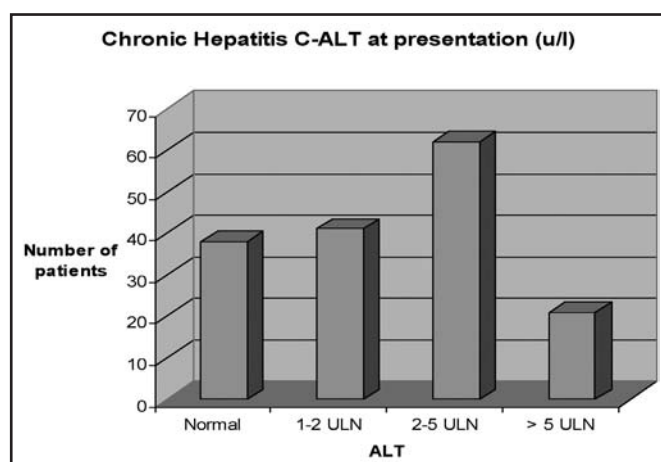
Table I : The demographic characteristics

Demographic Characteristics	CHB (n=746)	CHC (n=164)
Gender		
Male : Female (ratio)	515: 231 (2.2:1)	99:65 (1.5:1)
Mean age (range) in years	42.4 (11-84)	45.2 (15-74)
Ethnic Origin, n (%)		
Malay	285 (38)	57 (35)
Chinese	425 (57)	76 (46)
Indian	23 (3)	27 (16)
Others	13 (2)	4 (2)
State of origin, n (%)		
From within WPKL, WPP, Selangor	565 (76)	181 (24)
From other states	91 (55)	73 (45)
Source of referral, n (%)		
From public sector	557 (75)	134 (82)
From private Sector	178 (24)	26 (16)
Not available	11 (1)	4 (2)



ALT=Alanine Aminotransaminase
ULN=upper limit of normal (normal ALT=40 u/l)

Fig. 1: Number of patients by ALT level at presentation (chronic hepatitis B).



ALT=Alanine Aminotransaminase
ULN=upper limit of normal (normal ALT=40 u/l)

Fig. 2: Number of patients by ALT level at presentation (chronic hepatitis C).

challenges being the low rate and frequency of reporting from source data provider, limited funding and lack of dedicated staff. These factors had hampered efforts in the second and third year of registry work. However, with the support and commitment of the Ministry of Health, Malaysia and the Clinical Research Center, this registry has progressed and achieved some of its original objectives.

ACKNOWLEDGEMENT

The Ministry of Health, Malaysia for funding and other support. The doctors who contributed cases: Dr Asmarani Abdullah, Dr Sharmila Sachithanandan, Dr Chan Yee Ming, Dr Tan Ooi Keat, Dr Haniza Omar, Dr Dennise Khoo. The staff of the Hepatology Department, Selayang Hospital and the staff of the Malaysian Liver Foundation.

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