Uganda

Action for Rural Transformation (ART)

Community-based organisation

Moyo, Uganda

SURVEY HIGHLIGHTS


The organisation provided the following general statement regarding key hepatitis policy issues in Uganda:

National coordination. At the national level, coordination has been very slow, probably limited by resources. The constraints to the coordination are related to the involvement and engagement of players such as:

- Lack of central government support and funding. No government institution has been assigned to handle this highly prevalent disease.
- Limited donor support for Hepatitis B activities in the affected regions.
- Health facilities and health workers have not been adequately prepared for case management. A comprehensive policy for management of Hepatitis B virus has yet to be approved.
- The Ministry of Health, NGOs and community-based organisations should be supported to carry out capacity assessment and plan accordingly.

Awareness-raising, partnerships and resource mobilisation. A national task force for Hepatitis B has not been established, yet this is very important in steering awareness campaigns at the national, regional and district levels. The people who commonly serve as resources for raising awareness about issues in communities – health workers, politicians, and cultural and religious leaders – themselves have very little factual information on viral hepatitis. National booklets developed for health education have not been translated into local languages for information dissemination.

No clear partnership exists from national to grassroot levels, and integration of Hepatitis B activities at various levels is still poor in regard to resource mobilisation and awareness-raising.

There is a need for collaboration at the international level and for engaging government to continue to provide leadership to address this problem.

Resourced civil society organisations should work hand-in-hand with the government to move to the grassroots.

Local NGOs and community-based organisations could help in sensitisation but lack resources.

University/medical school study centres could be established in areas with high prevalence, such as the West Nile here in Uganda, to help in the study of this disease.

Prevention of transmission. Since 2002, efforts by the Ministry of Health to reduce hepatitis B infection in the country are being addressed although at a slow pace in the following ways:

- Vaccination of children with pentavalent vaccine that protects children against hepatitis B has been introduced in all the health facilities.
- The Ministry of Health has procured vaccine for more at-risk populations, especially health workers.
- Information, education and communication materials have been developed by the health education department, but they are inadequate in number and not translated into local languages.
- The Ministry of Health is encouraging health workers to use universal precautions in patient management.
- Phased out re-use of syringes by introducing auto-disabling syringes in all levels of care in public and private facilities.
- National medical stores are to take the lead in procuring reagents for hepatitis screening.

However this has not fully addressed the challenges of patients who are exposed and those with active disease as most facilities cannot do a baseline investigation for decision-making regarding initiation of treatment. No specific standard treatment guideline has been developed for case management.

Screening, care and treatment. Screening kits for hepatitis B surface antigen are being supplied but most often are in short supply, thus delaying or denying access to screening. Reagents for hepatitis B core anti-agent test and liver function tests are not available in most general and district hospitals.

The drug in use is lamivudine, which is restricted for case management of HIV. Authorities are reluctant to allow its use for management of Hepatitis B for fear of resistance.

Civil society should provide funding for training/retraining health workers to enable them to improve in case management.

Sources

http://www.monitor.co.ug/SpecialReports/Hepatitis-B-slowly-eating-up-West-Nile/46883/1947904/69kkuuz/index.html


http://ugandaharmreduction.wordpress.com/2014/01/15/mps-quiz-minister-on-hepatitis-b-prevalence/

The Government of Uganda did not respond to the World Health Organization survey for the 2013 Global Policy Report on the Prevention and Control of Viral Hepatitis in WHO Member States, and therefore the Cancer and AIDS Relief Organization could not comment on government information for this report.

The organisation provided the following general statement regarding key hepatitis policy issues in Uganda:

**Awareness raising, partnerships and resource mobilisation.** In Uganda, most people are ignorant about viral hepatitis due to lack of information, myths and misconceptions associating it with poisoning, no partners in place to avert vice. High costs limit service delivery due to mass poverty across the country.

There is a need to create awareness about hepatitis B, advocate for the formulation of effective guidelines and policies to address hepatitis B issues, urgent mobilisation of partners and funding opportunities to support hepatitis B service delivery to communities.

In bringing about these changes, the government will be responsible for:

- Developing friendly policies and measures regarding hepatitis B.
- Collecting baseline data on the prevalence of hepatitis B to influence the World Health Organization to prioritise and integrate its management into the health system.
- Building the capacity of health care providers and other stakeholders in the management of hepatitis B.
- Mobilising and allocating funds to combat hepatitis B.

**Other stakeholders’ responsibilities:**

- The community should promote sensitisation programmes by distributing information, education and communication materials for information dissemination.
- Civil society organisations shall collaborate with the government in mobilisation and service delivery.
- At the national level, the government shall support hepatitis B activities by developing implementation policies/ guidelines and allocating resources while advocating and providing technical support on hepatitis B at all levels and integrating it into existing health systems.
- The international community shall provide logistics to support service delivery.

**Screening, care and treatment.** In Uganda, chronic hepatitis B infection, defined as persistence of hepatitis B surface antigen for more than six months, has been demonstrated in 10% of the population but with a varying distribution due to limited knowledge and data issues about hepatitis B virus in regions in the country (ATIC newsletter, volume 6, issue 6, November 2009).

Hepatitis B screening services are not sufficiently accessible to most-at-risk populations, which include all children, sexually active adults and adolescents, discordant couples, people with HIV, diabetic patients, health care providers, house contacts with carriers and public safety workers with occupational risks, disabled persons, prisoners and pregnant mothers.

The proportions which are tested hepatitis B positive fail to meet funds for carrying out other profile tests to fit in the criterion for treatment initiation which impacts on their immune responses.

**Prevention of transmission.** There is a need to strengthen advocacy and partnerships for equitable access to quality hepatitis B information about screening, which is the entry to prevention and other services, as well as effective treatment of infected persons with hepatitis B so as to eliminate further transmission.

The role of the government in bringing about these changes includes accessing affordable testing kits, drugs and vaccines to the clients and building the capacity of health care providers about viral hepatitis B infection.

**The existing evidence about hepatitis B in Kasese District is based on data collected by the Cancer and AIDS Relief Organisation from March 2011 to December 2013:**

- Have treated 1,951 people for Hepatitis B surface Antigen (HBsAg); out of these, 1,705 tested negative and 242 tested HBsAg positive. Among those who tested positive, only 78 people could afford to raise funds for hepatitis B profile monitoring tests which determine initiation of treatment.
- Of those clients who tested Hepatitis B envelope Antigen (HBeAg) positive and or with abnormal liver function tests, 42 are on treatment for hepatitis B viral infection, whereas those who tested HBeAg-negative are being monitored.
- Have vaccinated 835 clients against hepatitis B viral infection out of 1,705 clients.
- Have treated nine patients with chronic hepatitis B viral infection.
- Have provided hospice care to 75 patients with severe pain controlled on oral morphine; out of these, four patients had cancer and HIV, 56 had cancer only and 15 other causes. Hepatocellular carcinoma and liver cirrhosis were leading with 29 patients. Thirty-three patients out of 75 died.

**SURVEY HIGHLIGHTS**

The organisation provided the following general statement regarding key hepatitis policy issues in Uganda:

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Despite the approval of treatment for hepatitis B viral infection by FDA like the injectable alpha interferon’s, orally administered ART, the patients have always failed to meet the cost of treatment leading to progression of cirrhosis and hepatocellular carcinoma due to high viral loads.

There is need for addressing the gaps/challenges that inhibit Hepatitis B prevention at the international, national, district and community level through advocacy, collaboration, sensitisation and capacity-building.

The role of the government in bringing about these changes includes accessing affordable testing kits, drugs and vaccines; building the capacity of health care providers about viral hepatitis; and creating awareness on hepatitis B viral infection.

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- The community shall promote sensitisation programmes by distributing information, education and communication materials for information dissemination.
- Civil society organisations shall collaborate with the government in mobilisation and service delivery.
- At the national level, the government shall support hepatitis B activities by developing implementation policies/guidelines and allocating resources while advocating and providing technical support on hepatitis B at all levels.
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Giving Hope Foundation (GHF) is an indigenous not-for-profit nongovernmental organisation based in Kampala, Uganda. GHF aims at restoring hope among vulnerable children and communities that have been affected by poverty, abuse, violence, disease and other natural calamities.

To mark World Hepatitis Day in 2011, Minister of State for Health – General Duties Hon. Dr. Richard Nduhuura made a communication to commemorate World Hepatitis Day. The minister committed to health promotion and education, routine immunisation, and vaccination of health workers and medical students, scaling up of sanitation and provision of safe water practices, early screening, infection prevention and control of health care waste management and control of all non-communicable diseases.

An awareness walk was held through Kampala city to commemorate the day and many Ugandans including health practitioners joined the cause.

In 2012, following a series of planning meetings for World Hepatitis Day, there was an outbreak of the Ebola haemorrhagic fever (Sudan ebolavirus) in Kibaale District (midwestern Uganda). The Ministry of Health confirmed this outbreak on 28 July 2012 following weeks of speculation about the cause of a strange disease that had many people fleeing their homes. Because of this outbreak, the Ministry of Health turned its attention and focused all of its resources to this cause; consequently, World Hepatitis Day was not celebrated in 2012.

In 2013, there was another outbreak in July which forced the Ministry of Health to allocate resources again to the emergency. The national celebration was rescheduled for a later date, but did not take place due to insecurity in the capital city.

There have been inquiries and calls from the parliament and other security organisations for the Ministry of Health to make a statement and combat the growing cases of hepatitis in Uganda that have not been sufficiently attended to.

The biggest challenge for civil society organisations involved in hepatitis is that there has been little involvement from the Ministry of Health, and we have found it hard to carry out some national activities that require its endorsement. The Ministry of Health has cited lack of personnel and resources for its lack of interest. But because of continued outreach and advocacy, there has been growing interest and involvement from the Ministry of Health since late 2013.

Government has a role in supporting the work and efforts of civil society organisations because we actually carry out activities that are meant to be performed by the government. Government also needs to be more open and reduce the bureaucratic process of acquiring information and access to key personnel.

Since civil society organisations work to support the efforts of government in Uganda, their roles include:

- Playing positive roles as strengthening the voices of the vulnerable and enhancing their participation in development processes.
- Representing and actively advocating for the interest of their members including hepatitis advocacy and support for patients among others.
- Influencing political agenda-setting and putting forward those social needs that represent the general demands of the population like including communicable diseases like viral hepatitis on the national agenda.

In 2014, we have seen increased interest around viral hepatitis in Uganda. The President of Uganda, during the National Resistance Movement Day on 26 January, made special mention of the need to raise awareness regarding this preventable illness.

The Ministry of Health together with other stakeholders is planning to hold a series of events across the country to raise awareness; screen and set up support for hepatitis patients; and commemorate World Hepatitis Day on July 28, 2014.

There is a need to integrate hepatitis activities with other similar government efforts like HIV/AIDS, tuberculosis and malaria programmes.

Donor agencies like the World Health Organization, Clinton Health Initiative, UNICEF, USAID and foreign embassies need to come on board to support the efforts of civil society organisations in raising awareness, vaccinations, treatment and support for hepatitis patients in Uganda.

With continued advocacy, 2014 is promising to be a breakthrough year with regard to hepatitis in Uganda.

* World Hepatitis Alliance member.
Uganda

The National Organization for People Living with Hepatitis B (NOPLHB)*

NGO – hepatitis patient group
Kampala, Uganda
www.freetocharities.org.uk/noplhb/

SURVEY HIGHLIGHTS

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The organisation provided the following general statement regarding key hepatitis policy issues in Uganda:

**Awareness-raising, partnerships and resource mobilisation.** Currently the awareness of the general public about hepatitis is very poor. Even among health care workers, the specialists seem to be better informed than the general physicians and other ancillary workers. Furthermore there is a lot of stigma and misconception attached to viral hepatitis among the general public. Policy-makers are aware of the issues but seem to be tied down due to other priorities and lack of funding. There is therefore a need for public awareness campaigns through the use of traditional communication channels spearheaded by the Government.

The Ministry of Health should start awareness programmes for health care workers through workshops and health economic studies to inform policy makers that acting on hepatitis can save the economy more than Government would spend. Collaboration exists among the National Organization for People Living with Hepatitis B, Uganda Gastroenterology Society and Giving Hope Foundation, and all are working towards the development of awareness and policies. The Government should leverage existing partnerships.

The Government should also extend the partnerships to include HIV and antenatal initiatives. Hepatitis can be easily combined with HIV initiatives as this would save infrastructure costs and also would ensure easier implementation of policies. The Ministry of Health should review HMIS to include hepatitis for proper data collection.

**Screening, care and treatment.** Lack of awareness, clear guidelines and referral system for testing, the diagnosis rate of hepatitis B and hepatitis C infections are very low. Hence the majority of cases present at a late stage, sometimes with complications. The high cost of hepatitis B and hepatitis C diagnosis is another factor contributing to lack of diagnosis. Generally 30% of hepatitis B cases and 45% to 70% of hepatitis C cases are eligible for treatment. However, 85% to 90% of hepatitis B cases receive treatment while only 1% to 5% of hepatitis C cases get treated. This disparity is mainly due to the unaffordability of hepatitis C treatment. Treatment for viral hepatitis is generally out-of-pocket. No government support or private insurance for treating viral hepatitis exists. The Ugandan government introduced HBsAg vaccine in the extended programme of immunisation for infants in 2002. However, this programme does not cover the vaccination of adults and at-risk population. Mothers are also still reluctant to have their babies immunized.

There is a need to conduct health economic studies to encourage support for diagnosis, prevention and treatment for viral hepatitis cases. Mothers should also be sensitised about the importance of immunisation programmes.

The Government should design proper guidelines to address diagnosis and treatment challenges and provide affordable sources of diagnostics. This would reduce cost of diagnosis and in turn increase the diagnosis rate.

* World Hepatitis Alliance member.