

Counselling needs of hepatitis B surface antigen (HBsAg) positive persons

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An action-oriented study was carried out in December, 1998 to explore the knowledge, perception, emotional reactions, and behavioural intention regarding hepatitis B surface antigen (HBsAg) positive test result. Opinions on counselling needs of the hepatitis B surface antigen positive persons were also explored. A qualitative approach using In-depth Interviews (IDIs) was conducted among 10 recently diagnosed hepatitis B surface antigen positive persons attending the Department of Medical Research (DMR) Vaccine and Diagnostic Clinic. Five men and 5 women participated in the study. Their age ranged from 17 to 51 years. All the respondents came to DMR Vaccine Clinic for voluntary testing of hepatitis B surface antigen. Some visits were job related and others were not. Most of the people tested to be hepatitis B surface antigen positive usually perceived the test result as a great threat to life. Common responses to the positive test result were surprise, fear, denial, and worry. The majority of the respondents did not know what the test positive result means. Even though the respondents were educated, they could not identify the disease transmission and consequences of hepatitis B surface antigen positivity properly. Their future behavioural intentions were vague and unclear. They all suggested that counselling to hepatitis B surface antigen positive persons was essential. When explored the counselling needs of hepatitis B surface antigen positive persons, the majority preferred being counselled in a group by a same sex counsellor. They also stressed that counselling service should be supported by a clinical and laboratory service.

INTRODUCTION

The hepatitis B virus (HBV) has infected more than 2,000 million persons alive today and 350 million persons are chronically infected carriers of the virus, at high risk of death from active hepatitis, cirrhosis, and primary hepatocellular cancer. Each year approximately 1 million people die from the acute and chronic sequelae of HBV infection [1]. Therefore, most people tested to be hepatitis B surface antigen positive (HBsAg) perceived the positive result as a great threat to life, and suffered from undue burden of emotional stress, resulting in reduced quality of life. As many HBsAg positive people may lack information and support, it cannot be taken for granted that they would change certain life styles and

behaviors with a view of preventing transmission of HBV infection to others.

HBV infection is hyperendemic in Myanmar with a 10 percent carrier rate, 60-70 percent infection rate [2], and Myanmar is trying to integrate hepatitis B vaccine into the Universal Child Immunization Programme. In the meantime, the Department of Medical Research (DMR) Vaccine and Diagnostic Clinic is providing vaccination with plasma derived HBV vaccine and diagnostic testing for HBsAg status, to clients at a very reasonable price.

From experiences of the clinic medical officers, these newly diagnosed HBsAg positive persons were greatly concerned about the positive result and were at a loss

to adopt an appropriate plan of actions to cope with the problem. This may be due to the fact that these people may lack appropriate information concerning HBV infection and support to enable them live positively with HBV infection.

Despite an unmet need, counselling services for HBsAg positive persons are not well developed in our country. Thus, it is necessary to explore as a baseline data about knowledge, perceptions and emotional reactions of newly diagnosed HBsAg positive people for the training and conducting of counselling sessions. This is, therefore, an action-oriented study to support the future hepatitis B prevention programmes aiming towards HBsAg positive persons.

General objective

To explore the knowledge, perception, emotional reactions and behavioural intentions concerning HBsAg positively and counselling needs of hepatitis B surface antigen positive persons.

Specific objectives

1. To assess the emotional reactions of the clients to a positive HBsAg test.
2. To explore the perceptions of HBsAg positive test result in respect to disease meaning, transmission, complication and social implications.
3. To find out behavioural intentions of the clients and opinion regarding counselling.

MATERIALS AND METHODS

An exploratory qualitative study design was used in this study. Using the dimensional sampling method, a total of 10 adults both male and female, married and unmarried were included in the study. The study was conducted at Department of Medical Research Vaccine and Diagnostic Clinic in December, 1998.

In-depth interview for each client was conducted by a trained moderator with the

assistance of a note taker and a cassette recorder. The discussions were transcribed, translated and mathematically coded. Commonalties were extracted through words, phrases and themes and re-coded and summarized. Then, the analysis framework was developed. The final analysis was done according to the major themes and sub-themes.

RESULTS

It is acknowledged that the information presented in this study may not be entirely representative of the general population. However, due to the qualitative nature of the study, the emphasis is on the content of the information gathered.

Reasons for testing

Among the studied subjects, all came to the diagnostic clinic on a voluntary basis. Most of the men were job related in testing the HBsAg. Some came to the clinic with family members for testing because it was a popular and dangerous infection.

"A lot of people are saying about the disease, and they said it is highly infectious. So I came and tested for it with a friend."

(An ongoing deck cadet, single)

"My husband is going to Singapore as a carpenter, I came with him and he told me to take the test while we are here."

(A pregnant mother of 2 children)

Emotional reactions to a positive HBsAg test

Most of the people tested to be the HBsAg positive usually perceived the positive result as a great threat to life. The most common responses are surprise, fear, denial, and worry.

"I came here to take a test and to vaccinate myself. I was so sure of myself that I won't have the disease. I feel something. I don't know how to express it. I can't believe the result. It's so surprising."

(A 32-year-old single deck cadet)

"I'm so afraid, I heard about the disease on the television by a liver specialist"

Saya U Khin Mg Win. I'm trying to keep calm. But still I'm so afraid." (Very afraid and so enthusiastic to inquire questions)

(A 37-year-old school teacher, single)

Perceptions about the positive HBsAg test

Majority of the respondents did not know what the test positive result means. They were mixed up with the disease. Some knew that it was due to an infectious organism. Followings are their responses.

"It's having a disease. But I don't mind. I'm old. I think it's bacteria. I've read and it's some form of bacteria."

(A 51-year-old, government officer, married man)

"I don't exactly know what it is. I've heard that it was due to pork. You see I eat a lot of pork."

(A single adolescent from Institute of Marine Technology)

Regarding the questions on hepatitis virus infection and its type, majority think that if they have the positive result they are going to suffer from some forms of liver disease in near future. When asked about the types, some respondents could answer correctly but some of them mentioned others such as liver cancer and dry liver (a local term used for cirrhosis).

"I don't know. I think it affects the liver. I know five types. They are crunchy liver, hard liver, dry liver. I don't know that if they are related to hepatitis or not."

(A pregnant mother of 2 children)

"I understand that it may be inflammation of liver. It is infectious. I don't feel anything"

(A 27-year-old single female)

Social implications

HBsAg testing in relation to work was one of the strongest reasons for testing HBsAg and about half of the respondents were job related in testing. Two youngsters were to enter a school, 2 men were to go abroad for working. A man who is a government officer came for testing without any reason in relation to job. Most of the women came

along with their spouses or friends to be immunized.

"I am worried, because I want to be a sailor. For the time being it's O.K., but people say that when you enter some country you need the vaccination certificate. I don't know what will happen as a consequence, but still I got depressed."

(A 32-year-old married male)

"Yes it does affect my work. I was going to attend the Institute of Marine Technology. My dreams were wiped away."

(A 17-year-old adolescent)

Among the interviewed respondents, half were married and others were single. Almost all of the respondents were not clear of the relationship between HBsAg positivity and marriage. Those who came with their spouses who were negative at the time of diagnosis took the immunization immediately.

"I don't know if there is connection. My wife is negative and she has been immunized."

(A 51-year-old government officer)

Possible mode of transmission

It was very interesting to hear from the interviewed respondents regarding their belief in possible mode of transmission.

"You see I eat a lot of pork. I have heard that it is due to pork. I myself like pork very much"

(A 17-year-old adolescent)

"I don't know how I got the disease. I have no idea about the transmission. You see I don't usually take injection. The only thing is I told my children to take out my heat"

(A pregnant mother with 2 children)

Knowledge about HBV in relation to transmission

Regarding to knowledge about HBV transmission, majority of the respondents could not identify exactly the mode of transmission. Irrespective of their educational status, they could only mention few types very vaguely.

“I think it can be transmitted through injection. I usually ask the doctor to use the disposable needle. I think you should also avoid eating pork. Because people say that if you eat pork it’s easier to die.”

(A 39-year-old married male with 3 children)

“I don’t know much, but I have heard of some things, injection needle, drinking water, food and chilli sauce can cause hepatitis. When people have low resistance the disease can occur.”

(A 27-year-old graduate women)

Knowledge about HBV in relation to its complication

The interviewed respondents could not differentiate between the disease and its complication. Most of them thought that if they have the HBsAg they were having the disease inside them.

“The complications are crunchy liver, dry liver, liver cancer. But you see I suffered from hepatitis when I was very young. If there were complications, during these years I would have died. But you see nothing has happened to me.”

(A 39-year-old married male)

“I know liver cancer, dry liver but you see all are mainly due to alcohol. A person may or may not develop the complications.”

(A 32-year-old single deck cadet)

Behaviour intentions

Most of the respondents wanted to get rid of the disease or organism completely. Almost all have positive behaviour intentions (apart from one old man). Even though the respondents were quite high in educational level, their behavior intentions were vague and unclear. They were also not clear of the preventive and healthy living in relation to the disease.

“I want to get cured. I’ve heard a lot of people saying indigenous medicines are more superior than western medicines in treating hepatitis infection. An indigenous healer who lives in front of Bogalay Market is famous. I am going there to see. And I have to watch my diet. I will advice my

family be tested and vaccinated.”

(A 39-year-old father of 3 children)

“I will separate my cup for drinking water. The main cause is water. I will also separate and use my own belongings. I will buy those big sterile water bottles for myself and use them as my own. I have to avoid another thing and it’s cold. To increase my immunity I will try to eat a lot of organ meat.”

(A 19-year-old single male)

Opinion regarding counselling need

All the interviewees said that health education is essential in prevention and control of hepatitis B viral infection. They thought that it should be strengthened to reach the general public. They also stressed that counselling of individuals with positive HBsAg is also in great need. Because when they were diagnosed they did not know what to do, to whom to go and how to prevent further spread. They all have different views in counselling and the responses are as follows:

	How	Sex	When	Where	What
1	Groups	Same sex	After alcohol hours	No preference	Disease process and treatment
2	Groups	Same sex	Suitable time	Private place but not too private	Counselling and service
3	Single	No sex differentiation	Appointment	No preference	Counselling service and support
4	Single	Same sex	Appointment	No preference	Disease process
5	Groups	No sex differentiation	No preference	No preference	Disease process media aids and its outcome
6	Groups	Same sex	Any time	No preference	Disease process
7	Single	Same sex	Any time	No preference	Counselling and service
8	Groups	No sex differentiation	Any time	No preference	Disease process and how to live with the positive result
9	Groups	No sex differentiation	No preference	No preference	Disease process and prevention
10	Single	Same sex	Appointment	No preference	Disease process

Those who preferred to have counselling given in a matter of groups or single had their own reasons.

"It would be better to give counselling in groups so that I can feel that I'm not alone and we can share our experiences."

(A 32-year-old single deck cadet)

Majority expressed that counselling should be given by same sex persons so that they could discuss more openly and frankly.

"I think it should be given singly by a same sex health personal. So I can also ask private questions and discuss more freely."

(A 19-year-old single male)

"I feel more safe talking to a same sex personal"

(A pregnant mother with 2 children)

Regarding time and place for counseling, majority had no preference. Almost all of the respondents stressed that counselling should be supported by service like clinical examination and blood testing.

"If you just talk and explain I would only come once or twice, no more. You should include a blood testing service and do clinical examination and explanation about the disease progress."

(A 51-year-old government officer)

DISCUSSION

In this study, it was evident that majority of the subjects who came for HBsAg testing were on a voluntary basis. Among them, most of the men were job related in testing the HBsAg status. This highlighted that job related HBsAg testing has become an important measure among the working community nowadays. Therefore, proper health education concerning hepatitis infection and its consequences should clearly be given to the high risk working communities (in a very positive manner).

According to our study we have explored that most of the HBsAg positive persons

misunderstood about the disease process and HBsAg positivity. They all thought that they will suffer from some form of sequelae relating to hepatitis. They perceived the HBsAg positive result as a great threat to their life. This suggested that threat caused by the disease/infection has already been alarmed into the community. But there are still misperceptions about the disease transmission and disease process. There are in two extremes, some perceive the HBsAg positive result as a life threatening condition and some think it's no use worrying about the disease. Thus counselling should be encouraged to the HBsAg positive persons, about the misperceptions and carrier status. During adulthood infection rarely leads to the carrier state in which only 10% of adults turn out to be chronic carriers. And among them only 25% of them are at risk of serious illness and eventual death from its consequences [2].

Counselling regarding hepatitis infection has not been properly performed in our country up to date. Not only in our country but also in many parts of the endemic world, preventive efforts mainly aiming at immunization have dimmed the importance of the carriers who are the major source of infection. Therefore, counselling of HBsAg positive persons should be done as an essential component in prevention of hepatitis infection.

In this study, all of the interviewees pointed out that counselling is essential and they have stated the various ways of counselling like individual and group counselling. Majority preferred to be counselled by the same gender (sex) so that they can discuss more openly about personal matters. They had no specific preference in regard to time and place for counselling. They all suggest that counselling should be done in accordance with a clinical service like blood testing and clinical examination. Thus, voluntary HBsAg testing accompanied by counselling is a vital role to play within a comprehensive range of measures for prevention and control of hepatitis.

Hepatitis B prevention and support should be encouraged widely to reach the general public. The potential benefit of testing and counselling for the individual include improved health status through good nutritional advice and earlier access to care and treatment/prevention for hepatitis B related illnesses. Counselling also plays a vital role as an emotional support for better ability to cope with the disease (or) test positive related anxiety. Other preventive measures like awareness for safer options for reproduction and child bearing, motivation to initiate and maintain safer sexual practices and safer blood donation practices should be included in the counselling discussions.

Recommendations

1. Counselling service and training of counsellors for hepatitis infection should be incorporated into the hepatitis prevention programme.

2. Clear and precise information regarding hepatitis infection should be given to the community.

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