Uncovering the Experiences and Needs of Patients With Chronic Hepatitis B Infection at Diagnosis: A Qualitative Study

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Abstract
Patients with hepatitis B face uncertainty at diagnosis. Information and support they receive at the early stage of the disease determine their adherence to follow up and treatment. This study aimed to explore the experiences and needs of patients with hepatitis B at diagnosis. A qualitative methodology was used. Nine focus groups (n = 44) were conducted to explore patients' feelings and reaction to the diagnosis, encounters with health care professionals, and their needs. The transcribed data were analyzed using a thematic approach. Most patients were not prepared for the diagnosis and many felt anxious and distressed. This was attributed to poor patients' knowledge, doctor's emphasis on disease complications, and associated stigma. Information about the disease was lacking and patients wanted to know more about the mode of transmission, natural progression of the disease, complications, and treatment options. There was a feeling of "passivity" among patients because there was often no active treatment available at diagnosis. This resulted in patients defaulting surveillance visits and missing the opportunity to start antiviral treatment. Therefore, there is an urgent need to provide sufficient information and education about hepatitis B to newly diagnosed patients, break "bad news" to patients with sensitivity, address their emotional needs, and emphasize on the rationale and importance of surveillance and treatment. This may entail public awareness campaign, implementation of pretest and posttest counseling, and educating doctors on how to communicate the diagnosis and management to patients accurately and sensitively.

Keywords
consumer health information, hepatitis B, chronic illnesses, focus group, qualitative research

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