

# Dealing with hepatitis: The impact of the family on an individual's experience of illness

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'The travel through illness is a long and winding road, coupled with disease misconceptions and social stigmas, illness has different meanings to different families.'

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## Introduction

At some point in our lives most people will contract an infection that interferes with our schedules as well as our disposition. We may find ourselves sick, unable to move, feeling bad and angry against no one in particular. Eventually the infection passes and we are able to return to the mainstream of our own lives. However, what if, that infection did not pass, what if it stayed and our lives were never the same. This article is about a disease, a family and the things that happened in between.

## The disease

Janice is a 20-year-old who developed yellow discoloration of both eyes 24 hours prior to her initial consultation at the outpatient clinic of a tertiary hospital in the Philippines.

Her history started with a low-grade, intermittent fever unaccompanied by other signs and symptoms. Her fever resolved after 4 days without medication. However, Janice developed epigastric pain, which she described as hunger-like, continuous, non radiating and not related to food intake. It was associated with anorexia, nausea, body malaise, muscle and joint

pains. There was no vomiting, diarrhea or constipation. At this stage the patient self medicated with antacids which allegedly did not alleviate symptoms.

The yellow discoloration of both eyes, prompted her to seek medical attention.

On physical examination her sclerae were deeply icteric, her liver span was 8 cm, non nodular and non tender on deep palpation. Chest, cardiac and neurologic examinations were all within normal limits.

The provisional diagnosis was acute viral hepatitis, probably hepatitis A. Laboratory work-up revealed a reactive hepatitis B surface antigen (HBsAg) and hepatitis B early antigen (HBeAg); anti-HBsAg, anti-hepatitis B core antigen, anti-HBeAg, and hepatitis A virus IgM were all non reactive. Liver function tests were all elevated.

Janice was eventually diagnosed as suffering with an acute infection, as well as chronic hepatitis B. This was not confirmed histologically as a liver biopsy was refused by the patient.

A lay person in the Philippines being labeled with hepatitis B is like being given a 'near death' sentence because of the social stigma attached to the disease. As expected, Janice and her family reacted with shock and disbelief. The response of her husband's family to her illness was to ask her to move out of their home.

A sudden, exaggerated decision precipitated by their fear of infection. Janice's pain and feelings of abandonment increased, as she had to deal with the reality of her illness and the reactions of her family to her disease.

The family's perception of the disease was greater than the reality of the illness. Because of the lack of knowledge coupled with issues related to familial relationships, the response of the family was out of proportion to the true condition.

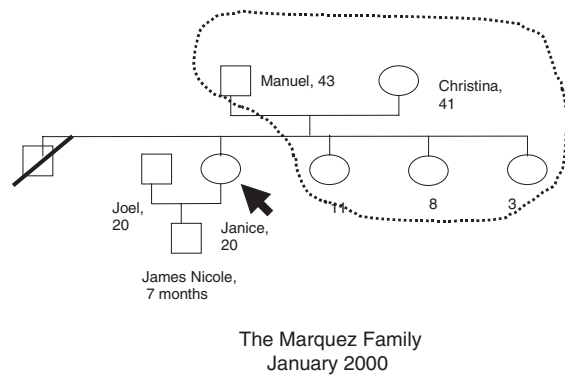
A family physician needs to know the family structure and dynamics in order to understand how the family reaction came about. Clinic sessions with Janice, her husband and her biological mother provided a

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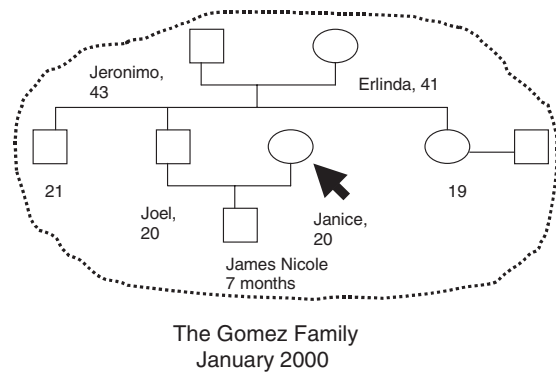
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**Figure 1** Genogram of the Marquez family, January 2000.



**Figure 2** Genogram of the Gomez family, January 2000.

glance into the familial relationships that subsequently helped in planning meaningful interventions.

## The families

### *The Marquez family*

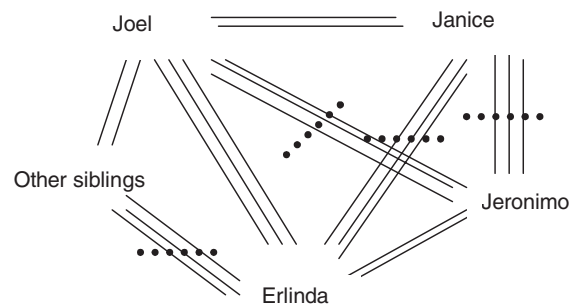
Janice is the second child in a family of five children (Fig. 1). Her eldest brother died at a young age while her other siblings are aged 11, 8 and 3 years. Janice's father, Manuel is aged 43, a former overseas contract worker; while her mother Christina has worked in radio communications. They are a family with young adolescent children whose set up is democratic with a nuclear structure. The Marquez family belongs to a middle class social pattern, who believe in hard work, economic security and self improvement through education. Finances and decision-making are divided between Manuel and Christina, as both are educated with stable employment. They believe in independence and their health seeking behavior and support during Janice's illness indicate a functional family support system.

Janice met Joel at 18 years of age. Courtship was short and marriage was inevitable as Janice became pregnant early in their courtship. Both stopped their college studies because of financial considerations and the newly married couple together with their young child went to live with Joel's family in Manila.

### *The Gomez family*

Joel, however, is aged 20, the second child in a family of three (Fig. 2). His parents earn their living by selling food products in the marketplace. Two of his siblings are unemployed and are dependent on the nuclear family for financial support. Joel belongs to a family with married children still living with their family of origin.

The Gomez family belongs to a lower social class pattern who sees life as a struggle for survival. They are

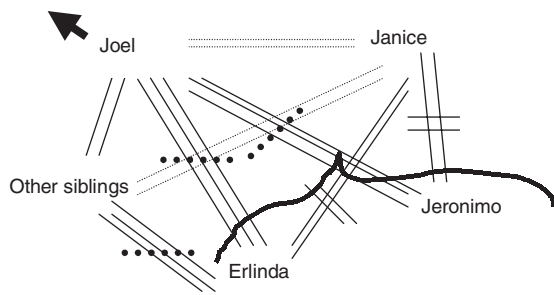


**Figure 3** Family mapping of the Gomez family.

a typical Filipino family in terms of decision making, externally patriarchal but internally matriarchal. The structure is extended as two members of the Gomez household are married, but still economically dependent on the family of origin. Their set up is authoritarian where there is an unquestionable obedience and conformity to parental guidance.

Their disease and health beliefs that accompany it are common to many Filipino households and can result in many misconceptions. They are traditional in their approach to medicine, leaning more to herbal medicines in the treatment of common illnesses. They do not believe in illness unless it is physically manifested. The family believes that hepatitis B is transmitted through air, food and common household utensils.

Janice belongs to the Gomez Family by virtue of marriage to Joel. Family mapping of the Gomez household indicates a system with an overinvolvement of parents towards the newly married couple. They often influence decision-making and the children usually concede to parental guidance (Fig. 3). There is a fairly balanced line of communication with good religious support group. However, cultural inferiority associated with economic deficiency and inadequate education led to the non use of health care facilities.



**Figure 4** Family mapping of the Gomez family after the acute phase of illness.

## The illness experience

### *The family illness trajectory*

#### Initial phase

This trajectory starts with the initial manifestation of the disease and is the stage experienced by the family prior to any contact with medical care providers. The nature of onset plays an important role in the ways families cope with disease.

In a normative illness trajectory, the onset of illness will ordinarily elicit family support. However, in Janice's case, the onset of illness started a family crisis. The early marriage of Joel and Janice was one of the contributing factors to the type of response to illness this family exhibited. It did not prepare them to be economically independent from their family of origin. Joel's failure to achieve a level of self differentiation from his family meant that even after his marriage, his loyalty was with his family of origin rather than to his wife. The health belief misconceptions associated with hepatitis together with the social stigma attached to the disease paved the way for the fear of illness.

Family mapping after the acute phase of illness showed further dysfunctionality among the household members (Fig. 4).

#### The second phase

The second stage of the illness trajectory is the impact phase referring to the reaction of the family and

patient to the diagnosis. Janice is a young wife and a young mother shattered by the discovery of her illness and loss of familial support. The initial reaction was sadness followed by denial and disbelief. The onset of symptoms and the disclosure of the disease entity were followed by a period of fear precipitated by uncertainty and the misconceptions about hepatitis B.

#### The third phase

The third stage of illness trajectory is the phase where the major therapeutic efforts are carried out. The problems perceived by Janice are icteresia, fear of transmitting infection, long term problems associated with the disease and long term treatment coupled with financial considerations. However, the only unspoken problem of the Gomez household seems to be their fear of transmitting infection to other members of the family. The goals of therapeutic intervention therefore were to decrease the physical manifestations of the disease as quickly as possible and to prevent long term sequelae associated with an active hepatitis B infection. The goals of psychosocial interventions were to strengthen marital ties, to re-establish communications lines between Janice and her in-laws and get the family to know and understand hepatitis B.

Medical interventions for Janice included Lamivudine capsules which was considered more economical than Interferon. This helped resolve the clinical and biochemical manifestations of the disease within 5 days of medical treatment. Other interventions included marital counseling, screening of family members accompanied by health education and correction of misconceptions regarding hepatitis coupled with the formulation of long term follow up care.

#### The fourth stage

The fourth stage of the illness trajectory was the family reaction to the outcome of treatment. In Janice's case, decreasing icteresia and health education had opened avenues that led to family support for financial considerations regarding her treatment.

Janice was not asked again to move out of her home.

## For further reading

- 1 Taylor Robert B. *Family Medicine Principles and Practice*. New York: Springer-Verlag, 1978.
- 2 Philippine Academy of Family Physicians. *Orientation Manual in Family Medicine*. Makati City: Family Health and Guidance Center, 1999.