

# A Dying Patient's Perspective on Truth-Telling

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Mr. H, a 60 year old farmer with liver metastases from a gastric carcinoma, had been in the hospital for quite some time. Jaundiced from his condition, he turned to one of the residents on rounds and said, "Several days ago, I asked you how much time I have to live, and you told me that I did not have too much time because I have a bad illness. This is not the way you should talk to patients." He then related his feelings about what information should be provided to terminal patients. At the end of the conversation, he consented to be interviewed for an instructional videotape.

The following is an edited transcript of the interview conducted by Dr. Glick with Mr. H. *Editorial comments are in italics.*<sup>1</sup>

## **Interview**

### **Where are you from?**

A small town of 60,000 in Iran. All 8,000 Jews left for Israel. We were small businessmen there, but here I became a farmer. I arrived in 1951. We lived in a shack for a year. In 1953 we arrived in the Negev. There was only desert and thorns. They put us into tents. Two years later we moved to huts, then concrete building, and finally they built us decent houses. We now live like human beings. We have a good life. We have everything we need. I have four cars. I have good children, all educated.

### **How did you succeed?**

I worked hard. I raised nine children, thank God. Now I can enjoy life. The only thing I am missing is some health.

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<sup>1</sup> Interview by Shimon M. Glick, MD. Video recording. 1991 (approx.). Ben-Gurion University of the Negev Faculty of Health Sciences, Soroka Medical Center, Beer Sheva.

**How long have you been sick?**

Two to three years. I was operated on for an ulcer. *He had not been told his diagnosis at the time of surgery.* I was healthy. Then I continued to work part time. My children and 45 employees do most of the work. I export almost a million liras worth of vegetables – celery, cabbage, lettuce, tomatoes.

**What happened after the surgery?**

Eight months ago, I suddenly got pain. My doctor made a home visit and gave me an injection. In the morning, she sent me to the hospital. They found what they found.

**What illness do you have?**

They sent me for an ultrasound examination. They found what I had. *He does not answer the question and never mentions the word "cancer."*

**What did they tell you?**

I was hospitalized for ten days. Then the doctors came on rounds. They knew what I had. I didn't know. I just knew that I had liver pains. Suddenly they all looked at one another. I said, 'Doctor, why are you embarrassed? Tell me. Do I have the same disease in my liver that I had in my stomach? I am not a coward.' He said, 'I am sorry, I could not tell you, but you said it yourself.' That's what he told me, really. *Note that the word "cancer" is not mentioned either by patient or physician.*

**What did you feel then?**

Nothing. I swear, nothing special. I am very strong. 'OK,' I told my doctor, 'I have to accept what fate gives me.' He sent me home and gave me a referral to the oncology service. I said 'OK' and went home.

**Did you ask any questions?**

No. Nothing. I already knew what I had.

**Did you want to know if it was serious?**

I didn't ask. I knew it was serious. I really knew. I'm no child.

**Were you afraid to ask?**

No, I wasn't afraid. I said, 'I know that it's a little dangerous. But I will continue as best I can. I have faith in God.' I went home and took the letter to oncology where Dr. B examined me. I asked, 'Dr. B, this disease that I have – *he didn't tell me what disease* – I know it is dangerous, but can I survive?' He replied, 'You are asking a question which I cannot answer. It's in the hand of God.' I was treated for 3 months – a course of IV treatment every 20 days.

**Was that difficult?**

Very hard. I vomited for three days each time. But when they asked me, I denied vomiting. *He attempts to impress the others with his courage.*

Then I went home. Three months later, they postponed my therapy because of a low white count. A week later I had pains and was treated by my MD. Dr. H had told me, 'If you have pains come right to my department, don't go to the ER.' But my family doctor told me to go to the ER. I waited in the ER for four hours. The wait killed me by the time I got to the department.

**Now you told us something on Friday about how the doctor spoke to you.**

This doctor – never mind his name – I asked him a stupid question. I asked him, 'With my illness how long can I live?' He said, 'I'm sorry, Mr. H, not too long. You have a very bad illness.' That was the first time. About a week later, I asked him again, and he gave me the same answer. Then I made a request from you on rounds. I took your hand. Do you remember?

**Yes.**

I said, 'I asked a question, and that doctor answered me that way, and then I became depressed.' Really. Instead of cheering me by saying, 'God is great. Life and death are in His hand. No one knows how long you will live. You ask silly questions.' He answered me that way! 'So I beg of you from now on, you should resolve that no patient should ever hear such words from you. Make that a tradition. Forever. Those are not proper words to tell a patient.'

**So you advise us not to tell the truth to patients?**

That's what my common sense tells me. When a patient hears optimistic views from his physician, he is greatly encouraged. It increases his longevity. It gives him a good feeling, a healthy feeling, doesn't break his spirit.

**Do you advise patients not to ask such questions?**

I thought ... I was so deeply depressed. *He opens up and admits being depressed.*

**You were depressed even before this episode?**

Yes. I was depressed. I said to myself, 'Maybe if I ask the doctor, he may encourage me; tell me, "Why are you depressed? It's all in the hands of heaven. Why do you ask such a silly question?" Instead, he answered me the way he did!

**You didn't ask the question in order to get information, did you? You were looking for him to tell you something that you wanted to hear?**

I was hoping that he would encourage me, raise my morale. 'You can still live a few years. You are strong, healthy. Others with this illness have lived several years, you can, too. You are a He-man.' *He is trying to convince himself that he has the power to overcome his illness. He finally articulates the real intent of his question – to extract from the physician a message that would give him hope.*

**You really are! After all that you have accomplished in your life you can probably overcome serious illnesses, serious problems.**

I am not sure. It's all in the hands of heaven. I pray to God for whatever life he will give me. Do you know why I don't want to die?

**Yes?**

Everyone has to die sometimes. You and I, God forbid. But because of my good family. I don't want to leave them.

**You have it good, here. I understand. I wish you long life and much pleasure from your family. I appreciate deeply that you are willing to teach us. Many thanks! Feel well!**

*The interview was therapeutic for the patient, granting him status and stature among the physicians. He was greatly cheered by the attention he received.*

**Reflections**

Here was a self-made man with little formal education, successful both in his family life and occupation, trying to cope with a terminal illness. For three years after the diagnosis of gastric carcinoma, which had been concealed from him, he functioned normally until the recurrence. The surgeon treating him, also an immigrant from Iran, in accord with his philosophy did not tell the patient his diagnosis even after the appearance of liver metastases.

In the interview, the patient describes the physicians' discomfiture on rounds due to a department policy of non-disclosure. The patient, while lacking advanced formal education, was quite intelligent and resourceful. He confronted the physicians directly with their embarrassment. Without ever using the word "cancer" – as if the word itself contaminates – he extracted from them the fact that he had metastatic disease.

He then described his response to the diagnosis. He initially denied any emotional reaction and attempted to prove to us (but more so to himself) that he was resilient and could overcome difficulties to which others might succumb. As the disease progressed, he grasped for straws of hope and desperately sought some encouragement in this direction. But the resident, a compassionate and honest physician trained in the Western medical mode of truth-telling, interpreted the patient's request for information as being just that and nothing more. But as the patient finally admitted near the end of the interview, he was not really seeking information, but he was rather hoping for words that would not foreclose any chance for continued life. These he did not get, to his disappointment.

As sensitive physicians, we must try to understand not just the obvious and superficial meaning of the patient's words, but also the hidden meaning behind the question – a daunting task. This interview is not presented in order to advocate a return to the policy of non-disclosure to patients with cancer, but to emphasize the individuality of patients, the importance of cultural differences, and the emotional devastation that may occur when all hope is foreclosed. Respect for patient autonomy may at times require that we withhold the full truth from patients. Perhaps the motto "The truth, the whole truth, and nothing but the truth" should only be used in the courtroom and not in the hospital.