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Caring for hepatitis C patients: Reflections on pharmacy and anthropology

Richard H. Parrish II, BSPHarm, PhD

The cultural meaning of drug use deserves more attention in clinical pharmacy practice and research. Worldview and life experiences can alter pharmacotherapeutic responses because what patients believe about their medications – within the context of their lives -- will influence medication use and assessment of response. Likewise, as evidenced by current patient safety initiatives, drug therapy systems can affect individual and population health. This connection between anthropology and drug therapy is seldom explored within the clinical context. Medication use is not random behavior. People make everyday sense of their drug therapies in some, often unique, ways. By making sense, emotional, cultural, psychosocial, and interpersonal nuance and significance is attached to the use of medicines. Moreover, medications are cultural symbols charged with meaning, accessed through a set of rituals, and managed in the context of individual life-worlds. To illustrate anthropology in action from a pharmacotherapy perspective, I describe my work with patients with hepatitis C, the most common chronic blood-borne infection in the United States, and present common themes that patients express during private direct care encounters.

“I never had any symptoms of disease.”

When I sit and listen with them, many of these patients say that they never had any symptoms of illness, and found out they had “the virus” on a routine check of blood chemistry. Often, the source and duration of infection is unknown. As one patient said, “I wanted to have everyone I knew tested to make sure they were not infected. Just because you don’t have any symptoms doesn’t mean you don’t have the virus.” If the source is known, many patients express guilt over their indiscriminant exposure to the virus. Their attention immediately turns to family or friends who might have contracted the virus from them.

I know where I got hepatitis C. I used heroin in the ‘70s, but have been clean for over 20 years. I was in and out of prison during that time, and didn’t really take any good care of myself.

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“Just give me the facts”

Misinformation about hepatitis is rampant in the general population. Many patients do not know what to think about the diagnosis, and begin to isolate themselves from their everyday worlds. To appreciate what hepatitis C patients experience initially after identification of hepatitis C antigen and diagnosis of active disease, it can be thought of as related to the grieving process. There is a sudden loss of self that comes from learning one has a chronic infectious disease, the fear of its impact on family and relationships, and the negotiation of changing life circumstances. Sources of information about hepatitis C for the newly diagnosed patient are conflicting and overwhelming.

Patients want the facts about the disease, their treatment options, and the impact of treatment on both the virus and them. “What is this going to do to me?” is a common question. Some patients have friends who have undertaken treatment

“These meds are changing who I am.”

For Jeff, anger, irritability, and hostility dominated his course of treatment. His young children actually helped Jeff make the connection between his irritability and lack of water consumption. “I was a rebel as a youngster, and got this tattoo in jail after a drunken binge.” His chief physical complaint was the shortness of breath he noticed due the nature of his work; he climbed telephone poles for a living. I saw him and his wife on several occasions to discuss the implications of the virus within their family. When his 6-month viral load returned unchanged, I really thought he would blame me. In concert with my collaborator, (Jeff wanted me there with him for his appointment) we discussed options for continued treatment in a protocol for non-responders. However, due to a long travel distance and the potential impact on his work, he declined, saying he didn’t think the virus would kill him anyway. He gave the virus his best shot, and thanked me for my care.

“I’m sick all of the time.”

Once they get over the “treatment hump” (which varies for each patient, but seems to take from 6 weeks to 3 months), long-term issues begin to emerge as well as queries related to their initial information overload. “What does the viral load mean?” “Is my liver getting better?” “What are my chances of ridding me of the virus?” “Are my spouse and children at-risk from my hepatitis C?” Often, patients become depressed (expressions of pain, anger, and

sleeplessness as well as sadness are common) from either dealing with the virus and/or the treatment. Then, they usually get used to the somatic effects of the medications, unless dosage adjustments are needed due to low blood cell counts (platelets, white cells, and/or red cells). For many, dosage adjustments are an indication to them of potential therapeutic failure, and can invoke fear and heighten anxiety. Adjustments can also be problematic because many patients have feelings as they did at the beginning of treatment (flu-like symptoms, headache, and fatigue). Some express anger at having their doses reduced because it decreases the virus's exposure to drug. They perceive and express this as failure. Constant reassurance is necessary to keep the patient engaged in the plan. Often, normal stresses in life are magnified because the medication can increase irritability. Near the end, many patients express a lack of motivation to complete treatment. They are tired of twice-daily capsule administration and weekly injections. For many patients, timing of their final medication supply order is fraught with over-supply or under-supply.

"Since I have no virus in my blood, I can stop treatment, right?"

Another patient, Larry, a treatment naïve middle-aged man, at first did not want anyone in his family to know he was taking treatment. "No one knows now, and no one will ever know I'm taking treatment." I never understood why except that he preferred to solve his problems without family help. Later, I realized that he never received much help in his family of origin. His parents (deceased) as well as he and his sister had alcoholism and suffered a great deal of physical abuse from each other. During treatment, he learned that his sister was positive for hepatitis C. He prayed right before he gave his first injection of interferon in the office. His greatest concerns stemmed from making sure he understood what the viral load meant so that he could minimize both future side effects and insurance expense. We needed to return to this issue monthly, especially when his result was undetectable at 6 months because he wanted to stop treatment. He weighed his persistent shortness of breath against the benefits of sustained viral response (an undetectable viral load 6 months after stopping treatment), and decided to continue each month until finished. However, he made this decision every month after weighing the evidence at hand.

"I was ready of punch out the guy's lights."

My first patient, Kevin, was a relapsing, treatment-experienced middle-aged businessman with a ten-year history of active disease. This was his third time to begin therapy, this time with combined pegylated interferon (long acting) and ribavirin. He kept a journal of events, thoughts,

and feelings that he shared with me as part of our plan. In the journal, he described the effects of his treatment in his relationships at work and home, and with his wife and relatives. Much of his self-observation described his level of energy and motivation. "Difficult to concentrate at work. Thought about hiring others to calculate job quotations." He used the journal to get through the first several months of treatment, and thought writing very therapeutic for him. During his course, he had several episodes of shingles and neutropenia (low white blood cell count), and persistent headaches, all that required medical management. His interferon dosage was reduced because of his low count until he received blood cell growth stimulating factors. The virus was undetectable in his blood at 6 months, a positive sign that he may not relapse (he wants to re-test his viral load when he feels badly, not at the usual 6 month post-treatment). He has regained weight and pre-treatment activity levels, and no longer struggles with insomnia or depression. He became a trained facilitator for the local hepatitis support group, and now provides invaluable insights to others struggling with the virus or contemplating its treatment.

"I want to cure this thing this time. Let's be as aggressive as possible with the doses."

John was anxious about treatment from the beginning. He had enrolled in a protocol for hepatitis C, but developed anemia and stopped treatment. He has been married for 12 years, and has four children under age 11. His treatment is complicated by his obesity; he weighed over 350 pounds at treatment initiation. He also wanted to loose weight as well. We made and received a special appeal to Medicaid for a weight-based dosage regimen (we both agreed to be aggressive with treatment) because the scientific literature revealed poorer outcomes for obese patients with fixed doses. His major reason for beginning treatment was he wanted to be around for his children. "Let's be aggressive with the treatment and push the doses as high as possible. I'll take however much I can stand." On initiation of treatment, his level of anxiety was compounded by side affects (peripheral tingling, shortness of breath, and sexual problems). I advocated for him with his other medical providers, and kept them in contact via my progress notes. I received a page from Jon on a weekly basis until he reconnected with his extended family in Rhode Island. He told me that an uncle had taken interferon for cancer, and drank a lot of water to feel better, which Jon and I discussed on every visit. He had made it over the treatment hump, and decided that the most important thing for him to do was to "kill the virus." He would stop worrying about his sexual problems, his alopecia, and his blood pressure (Stage 2). However, we needed to negotiate his ribavirin dose due to

incessant peripheral tingling. According to the literature, 1200 mg daily was his “ideal” dose. According to the patient’s level of tolerance, 800 mg was the maximum he could take. A dose of 600 mg was my minimum. He regulated it between 600 mg and 1000 mg depending on how he felt. At month five, he developed an exacerbation of asthma that prompted an early determination of viral load. Unfortunately, he did not respond despite adhering as best as he could to therapy.

Recommendation

While the promises of a cure range between 45 and 75%, infection with the hepatitis C virus and its treatment place many challenges to everyday living. Like those living with cancers, patients medicating with pegylated interferon and ribavirin often feel much worse than the disease itself. Sitting with and listening to these patients can provide the clinician with an enhanced understanding of the patients’ medicating experience and a more enriched meaning above and beyond the histology, biochemistry, hematology, and virology of the disease. More observational and interview studies are needed that bring pharmacy and anthropology in closer proximity to inform and contextualize the meanings of medication use in modern societies.