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# LEARNING THE PATIENT'S STORY

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**OBJECTIVES:** *To provide a brief history on narrative medicine and highlight its importance in providing quality patient care.*

**DATA SOURCES:** *Explains narrative medicine using published, peer-reviewed literature and highlights some of the literary, medical, sociological, and communication perspectives that contributed to the narrative medicine movement.*

**CONCLUSION:** *A commitment to the patient-provider relationship and knowing the patient's story is a critical aspect in providing quality cancer care.*

**IMPLICATIONS FOR NURSING PRACTICE:** *Teaching oncology nurses skills that are grounded in narrative medicine will improve health care by increasing the nurses' knowledge of their patients and strengthening the nurse-patient relationship.*

**KEY WORDS:** *narrative medicine, patient-centered medicine, patient's story, reflective journaling.*

**T**wenty-three years ago, I was 45 years old, a professor in the Department of Communication at the University of Oklahoma, and married to a physical therapist. On April 24 of 1995, just 5 days after the horrific Oklahoma City bombing of the Federal Building, I confronted more bad news: my internist told me I had a "significant abnormality" in my abdomen.

As oncology nurses, you know more than anyone else that cancer treatment has really changed in the last 20 years. No one tried to elicit my story in 1995 when I was diagnosed with stage 4, follicular, small cleaved-cell, non-Hodgkin's lymphoma. I was very conscious of not wanting to waste

anyone's time by offering extraneous, non-medical details about my life. Not that I was ever asked. . .

Honestly, I can only recall two encounters with nurses during my treatment, neither of which was particularly positive: the first was with a young nurse who relieved me with news about my initial bone marrow aspiration; she cheerfully assured me before I saw my oncologist that there was no cancer in my bone marrow. But she was incorrect.

The oncologist quickly told me that, in fact, cancer WAS in my marrow (as it was in 70% of patients presenting with my kind of lymphoma). And thus it was incurable (not a cancer patient's favorite word). I recall feeling so elated about the nurse's news and then so immediately fearful when I met with the oncologist. My second nurse encounter came during my therapy.

I participated in a phase III clinical trial. Until I saw the consent forms, I had no idea that my cancer was stage 4 (nor did anyone inform me that stage 4 didn't necessarily mean the same thing with blood cancers as it did with solid tumors). My therapy involved 8 months of chemotherapy, followed by 12 months of interferon alpha. I was told very hurriedly by my oncologist that I'd probably lose my hair, maybe feel fatigue after receiving chemo, but

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that I shouldn't have more pernicious side effects. Actually, I was able to teach my afternoon college class after getting chemo in the morning. I did not lose my hair, though a friend had helped me purchase a beautiful, expensive wig (with lots thicker, prettier hair than I had naturally!). I never used it.

While my chemo was really easy, I did fault my health care providers for failing to give me sufficient information about possible side effects of interferon alpha. Likely, I was given some written material about this, but I recall almost no talk about it. Again, when test results after the chemo revealed that the massive abdominal tumor was shrinking, everyone was in an upbeat, congratulatory mood, and ready for the next phase! I remember as I walked out of my doctor's office, the nurse briefly interjected: "You're not planning to work the year you're on interferon, right?" This was the first I'd heard of not being able to work. Of course I was planning to work. The nurse said casually that interferon often produced flu-like side effects so many people could not work while they took it.

I administered my own interferon injections on 14 consecutive days of each month for 12 months. After the first several months, I felt like I was injecting myself with poison for those 2 weeks. Of course, interferon is a natural substance, a protein, but I was taking massive doses of it. And it did make me progressively sicker. I was able to teach but just barely because of fatigue and diarrhea. By the 8<sup>th</sup> month I was on it, I was so sick one week that I lost 10 pounds and missed my nephew's graduation.

I had not been forewarned enough about possible physical side effects of interferon, but it was the psychological side effects that were even more debilitating. The substance-induced depression was like nothing I'd ever experienced. No one had suggested a proactive antidepressant – I had to ask my local oncologist for one. And it helped, but not before I'd spent one of the darkest periods of my life. One day my husband commented in exasperation: "Do you have any idea how hard it is to live with such a depressed person?" We were divorced within a year of my clinical remission. (I doubt that knowing in advance about the possible side effects of interferon would have salvaged that marriage.)

I tell you this long story of my own cancer because there was a minimum of anything psychosocial in my cancer treatments. There were no stories elicited and none told. It was all about reducing, hopefully eliminating, the detectable

presence of cancer in my abdomen and in my bone marrow. If that were working, there didn't seem a need for social talk – and I was complicit in that. I wanted to be a grateful, optimistic, forward-looking patient. I was almost always a "good patient."

I only know in retrospect that I should have been far more assertive in telling my story, even in complaining about the exclusive biomedical approach to my treatment. And I think both my oncologists and my nurses should have tried to know me more as a unique human, not as one more patient waiting to be seen by their esteemed oncologists in the hematology clinic.

When the patient's voice is heard and considered, a different focus emerges. Rita Charon, MD, PhD, is credited with the narrative medicine movement and explains:

Narrative medicine began as a rigorous intellectual and clinical discipline to fortify health care with the capacity to skillfully receive the accounts persons give of themselves – to recognize, absorb, interpret, and be moved to action by the stories of others. It emerged to challenge a reductionist, fragmented medicine that holds little regard for the singular aspects of a patient's life. . . .to widen the clinical gaze to include personal and social elements of patients' lives vital to the tasks of healing.<sup>1(p1)</sup>

Dr Charon began a program in narrative medicine at Columbia University in 2000. The Program in Narrative Medicine "is based on the premise that the care of the sick unfolds in stories; that individuals experiencing illness need to share their narratives, and clinicians need to listen fully. Caregivers have stories too, and voicing these stories helps them more fully understand, experience, and deliver care to those who are sick."<sup>2(p34)</sup> The program trains health care professionals as well as trainees in such disciplines as medicine, nursing, social work, physical therapy, psychoanalysis, and pastoral care, in addition to offering workshops and other services for patients and families experiencing illness.

Many of Dr Charon's predecessors illustrated and/or extolled the value of attending to the lived experiences of illness of patients and family members: some of these were literary (eg, Tolstoy<sup>3</sup> and Sontag<sup>4</sup>); others were MDs (eg, Arthur Kleinman<sup>5</sup> and Howard Brody<sup>6</sup>), and sociologists (eg, Arthur Frank<sup>7</sup> and Elliot Mishler<sup>8</sup>). Table 1 illustrates

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