

# What Happens to My Body - Happens to My Life!

## Disease vs. Illness Talk

### Covenantal and Reciprocal Relationships

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Physicians can diagnose and treat diseases of the body with a language of medicine, but do not often use an illness language. In his book<sup>1</sup>, Arthur W. Frank describes illness as the experience of living with a diagnosed disease. Often patients must experience the implications of illness on their own with little preparation or resources. When confronted with only disease talk, patients must find a healing self-language, especially when the disease is chronic and will eventually bring harmful complications to an otherwise healthy body, mind, and spirit. A patient expresses, at deeper levels of consciousness, the following thought -- "What happens to my body happens to my life."

A physician's talk is about a patient's disease and explained in terms gleaned from technology, science, and insightful experience. It is usually not about the patients' experiences of fear, frustration, and a possible impending interruption of life as they know it. Patients are left to their own devices to find another language to understand and cope with the future. But the fact is that no matter what happens to the body, a dramatic change has begun in the patients' lives and the lives of their family members. This realization demands openness to other resources which may lie dormant in the person. These resources go transcend body language to a mind and spirit language.

There are significant differences between the languages of disease and illness. A physician is trained to talk in a disease language such as reporting the results of tests, but a patient's talk is in an illness language such as "What does these results mean for my life and the life of my family?" Regrettably, at the proper time, the patients learn how to use the disease language, as if the body were someone else's.

Illness talk begins where disease talk ends. Illness is the experience of living through the disease whether it is chronic or finds a termination. Illness is considered in terms of fear, frustration and of being inside a body that is breaking down. It talks of unfamiliar ground for living as usual. Many express this change in such words as "I don't feel like myself and I fear I will never feel like myself again." Their

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<sup>1</sup> Frank, A. W. *At the will of the body: Reflections on Illness*. (1991). Houghton Mifflin Company, Boston, New York.

Miller, W.L., Crabtree, B.F, Duffy, M. B., Epstein, R. M & Stange, K.C. Research Guidelines for Assessing the Impact of Healing Relationships in Clinical Medicine. *Altern Ther Health Med*. 2003 May-Jun;9(3 Suppl): A80-95 (<http://www.ncbi.nlm.nih.gov/pubmed/12776467>.)

narrative is about loss and fear of drastic changes in their lifestyles. For the normal narrative of life contains personal hopes and disappointments, joys and sorrows, well-being markers. When that narrative is interrupted with markers such as blood counts, size of tumors, blood pressure, and temperature levels, the normal narrative of life is disrupted

In disease talk, the body is central. In illness talk, there is no such thing as a body separated from the mind and spirit, only my body as one experiences it. In disease talk, there is a charting of the progression of a problem, but in illness talk there is a story, a narrative, about moving from a perfectly comfortable body to one that forces the person to ask: "What happens to me in the future?"

Due to the scarcity of time given the patient-physician interaction in medicine today, disease talk continues to dominate the interaction of the patient and the physician. A patient expressed the patient-physician interaction in this way: "Talking to physicians reminds me of what I am not supposed to say or express. I can feel the illness—my whole life experience—but I cannot talk about it. I can only talk about my disease and not my illness experience. How am I supposed to live with disease?"

Healthcare is placing more emphasis on the healing quality as in positive relationships engendered between patients and healthcare professionals. This additional dynamic relationship supports the quality of patient care by re-enforcing the role of a patient's attitude and spiritual strengths and recognizing the reciprocal healing that healthcare professions experience because of a positive healing relationship.

Two examples of recent efforts at Ochsner to foster a closer healing relationship between healthcare professions and patients, or to include more illness language, are the covenantal statement developed by the transplant team and the statement on reciprocal healing from the Institute of *Medicine, Education, and Spirituality at Ochsner Health System (IMESO)*. Both statements reflect a growing awareness of the value of helping relationships in therapeutic settings.

The transplant team has developed and accepted this Patient-Transplant Team Covenant.

## Patient-Transplant Team **COVENANT**

As the **Transplant Team**  
and partner in your healthcare,  
we commit to always:

As a **Patient** and partner in my  
healthcare, I commit to always:

### VALUE YOU AS A PERSON

- Recognize you as a whole person.
- Respect your dignity, values and beliefs.
- Keep your information private unless you give us permission to share.
- Carefully listen to what you have to say.



### RESPECT

### VALUE YOU AS PEOPLE

- Recognize you as people committed to my well-being.
- Respect your expertise and experience.
- Be very clear about what information is okay to share with others.
- Carefully listen to what you have to say.

### TELL YOU THE TRUTH WITH COMPASSION

- Help you feel comfortable sharing your doubts and fears.
- Be honest about your health conditions and how you respond to treatment.
- Tell you about your medical condition in a timely manner.



### TRUST

### TELL YOU THE TRUTH WITH CONFIDENCE

- Be able to talk about my doubts and fears with you.
- Be truthful about my health, treatments and how I am following your instructions.
- Tell you all I can about my health in a timely manner.

### INCLUDE YOU AS AN ACTIVE TRANSPLANT TEAM MEMBER

- Partner with you to agree on your best healthcare plan.
- Coordinate with all who provide you with healthcare.
- Answer your questions as best we can.
- Include your caregivers as part of your transplant team.



### PARTNERSHIP

### BE AN ACTIVE MEMBER OF MY TRANSPLANT TEAM

- Partner with you on the healthcare plan I agree to follow.
- Tell you about everyone who provides me with healthcare.
- Ask you right away when anything is not clear to me.
- Include my caregivers as part of my transplant team. Bring a caregiver to all my visits.

The Executive Committee of the Institute of Medicine, Education and Spirituality at Ochsner has approved for consideration of all at Ochsner a statement about reciprocal healing. It is hoped that this will be a “discussion starter” at Ochsner.

### The Reciprocal Healing Statement:

Illness is a multifactorial mosaic experience because it affects the body, mind, and spirit. Any illness has the potential to change the patient, and the healing experience has the potential to change the healer. In this reciprocal relationship, both the patient and the healthcare professional can find meaning and wholeness through enlightenment, compassion, and wisdom.

Establishing such a reciprocal healing relationship requires healthcare professionals to go beyond the sole consideration of the mechanisms of disease and illness and to see each patient as a *person*—a unique human being. When this reciprocity occurs, both the one seeking healing and the healer enter, consciously or not, into a spiritual—a self-transcendent—realm

Healthcare professionals play a significant role in humanity’s desire for wholeness and well-being. They apply the principles and practices of science tethered with understanding to form the compassionate relationship Dr. Ochsner described when he said that we are “treating individual human beings who are ill rather than treating a disease.”

The Ochsner Institute of Medicine, Education, and Spirituality acknowledges and supports reciprocal healing in medicine.

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IMESO staff seeks comments about this article and, specifically, about the two examples of reciprocal care. For more information and/or comment on the article, please contact IMESO at 842-6941.