

NARRATIVE PROPOSAL DRAFT II

“Through my patients’ stories, I learn how and why people suffer, and how they heal”
(Squier, 1995)

SUMMARY OF PROJECT.

BACKGROUND and RATIONALE. Physicians must answer two major moral issues in their training: 1) What kind of doctor do I want to be? 2) How do I want to relate to my patients? (Mathiasen) “Caring” comprises a key component of most physicians’ responses . Physicians want to be caring doctors, and they want to relate in a caring manner to their patients.

What exactly is caring in the context of illness? Caring has been defined as consisting of receptivity (acceptance and confirmation of the inherent value of the patient); relatedness (an assumption that all human beings exist in relationship with each other and are therefore mutually obligated); and responsivity (commitment to the one cared for) (Homes and Purdy, 1992, in Taylor, 1997). Caring depends, at least in part, on the physician’s ability to see the patient as a person, rather than as an object, and to develop a human, as well as a technical, relationship with the patient (Nelson, Meyer, Wiltz, 1995). Compassionate, caring medicine requires the emotional engagement (Coulehan, 1995) that occurs when the physician is able not only to cognitively grasp the patient’s fears and feelings, but to imaginatively experience them.

For physicians faced with the pressures and multiple responsibilities of modern medicine, caring attitudes and behaviors can be difficult at the best of times. However, certain patients elicit more sympathy than others (Coulehan, 1991), while others become labeled “difficult.” These latter patients are frustrating and annoying for physicians, even at times a source of pain and suffering (Charon, 1986). It is often a particular challenge for physicians to evoke caring responses in these clinical encounters.

Physician caring can be stimulated using a variety of methods, but one relatively unexamined approach is through the use of patient narrative (Moyle, Barnard, Turner, 1994). For our purposes, patient narrative here refers to the patient’s illness story, or how the patient constructs and interprets the meaning of illness in the context of lived experience (Helfrich, Kielhofner, 1994). It has been remarked that storytelling is the fundamental way in which people make sense of their lives (Rennie, 1994). Since narratives can evolve through retelling, they also provide an opportunity for the creation of new stories with new meaning (Goolishian, 1990) Thus, the act of creating narrative can change one’s relationship to events and the meaning they are perceived to hold (Mishara, 1995). Without a shared story, there can be difficulty agreeing on a course of action (Miles, 1992). When patient’s story is ignored, the patient feels worse - more isolated, more suffering (Donley, 1995).

Awareness of the patient’s narrative permits the physician an insight into the “universal singular,” (Denzin, in Robinson, 1990), ie., the existence of universal verities contained within an individual case. Others have pointed out that once one takes on the “lived meaning” of another, the possibilities for caring are increased (Baker, Diekelmann, 1994).. Appreciation of patient narratives can enhance physician empathy, help the physician follow the thread of a complex and chaotic experience, adopt another’s perspective, tolerate ambiguity, recognize multiple, sometimes contradictory meanings

within experience, and stimulate moral reflection (Hunter, Charon, Coulehan, 1995).. Howard Brody has introduced the concept that, through patient narrative, the physician can see in what ways the patient's story is "broken," and how it might be healed (Brody, 1994).

The principle of narrative incommensurability (Hunter, 1992; Tsouyopoulos, 1994) between physician and patients, which states that definitionally and functionally patient and physician narratives reflect different realities, suggests the need to remind physicians periodically of the patient's narrative. Yet, in the era of managed care, progressively less attention is paid to elucidation of patient narrative. Productivity guidelines offer less time to develop the trust that allows the patient's story to be interpreted with confidence (Donley, 1995). Increasingly, the purpose of the medical narrative is to collectivize patients into diagnostic, prognostic and management categories. After the often hurried and diagnosis-focused initial history, the narrative moves further and further away from the patient's lived story (Marta, 1997). Yet it is possible to argue that a successful doctor-patient relationship is rooted in a shared understanding of this story, and its incorporation into the physician's agenda for assessment and treatment. Understanding of patient narrative is particularly important in situations where patients are perceived as difficult and frustrating by their physicians.

SPECIFIC STUDY GOALS. The purpose of the proposed study is twofold. First is to demonstrate that when physicians have a more comprehensive and coherent understanding of their patient's illness story, they are less likely to perceive the patient as difficult and frustrating. As a corollary of this statement, we believe certain patient narratives (ie., those that adopt a rebirth or heroic positive stance) will be more likely to evoke positive responses from physicians than will sad, chaotic, or tragic stories. Secondly, in the intervention phase of the project, we will demonstrate that sharing the narratives of difficult patients with their physicians will result in more caring, sympathetic attitudes toward these patients, and a reduction in their perception as difficult.

STUDY DESIGN, RESEARCH QUESTIONS, and HYPOTHESES: A comparison study looked at 20 difficult patients and attempted to elicit their story while in the hospital (Ventres,1992)

The Phase I hypothesis is that when physicians are able to describe their patients' narratives in greater detail and with greater coherency they will rate these patients as less frustrating, have better continuity with them, and achieve better patient satisfaction than when this narrative awareness is lacking..

SUBJECTS AND RECRUITMENT METHODS

Exclusionary criteria: pregnancy, new patient, over 65, non-English speaking, don't know their doctor

PROCEDURES : Phase I of the project will examine the illness narratives of physician-identified "difficult" patients ; and a comparison group of patients with similar diagnoses but who are not perceived as difficult; and to look for thematic similarities and differences. Subjects will be 20 patients identified by their physicians as difficult; and 20 comparison patients with similar diagnoses and severity of symptoms also identified by their physicians but who are not perceived to be difficult. Participating physicians will be family medicine physician faculty.

STUDY I: The purpose of the proposed study is to examine the illness narratives of physician-identified “difficult” patients ; and a comparison group of patients with similar diagnoses but who are not perceived as difficult; and to look for thematic similarities and differences. Patients will also be assessed for level of satisfaction with care. The patients’ physicians will also be interviewed to determine to what extent they are aware of these themes and symbolic meanings in their patients’ constructions of their situation. Each physician will complete a Practitioner Perception Scale on all subjects from their practice. They will also participate in a half-hour open-ended interview in which they will tell the “story” of their history with this patient, discuss their frustrations, and describe their view of the patient and his/her illness.

Patients will also be assessed for level of satisfaction with care. The patients’ physicians will also be interviewed to determine to what extent they are aware of these themes and symbolic meanings in their patients’ constructions of their situation.

Phase II of the study will be a randomized trial focusing on modification of the relationship between difficult patients and their physicians. The randomly assigned experimental group will consist of three interventions: 1) The physician is asked to recount his/her understanding of the patient’s story, to help develop empathy while reestablishing a level of clinical objectivity (Charon, 1986) or steadiness (Coulehan) 2) The patient tells his/her story, Patients will also complete a one hour interview in which they describe the “story” of their illness and the “story” of their health care for this illness. They will agree to participate in two half-hour follow-ups to clarify aspects of their narratives. in itself providing an opportunity for therapeutic healing (Pennebaker) 3) The physician reviews a “cleaned” version of the patient story. What will be presented to physicians is not a qualitative summary of what “most patients” in this situation feel, but rather the “complete text” (Ayres, Poirier, 1996) of a patient they are actually treating. This intervention is a way of returning the patient’s story to the physician, reminding the physician of this story Physicians will also be asked to identify new insights, information they obtained from the patient narrative.

The control group will consist of difficult patient-physician dyads who undergo only Usual Care. Both groups will complete a baseline battery of assessment instruments, measuring physician perception of patient and level of caring toward the patient; patient satisfaction and patient perception of symptoms and level of functioning. The battery will be repeated in 3 months for the control group, and immediately after and 3 months after intervention for the experimental group.

Patients will be offered \$10 to complete Phase I and Phase II control group study activities. They will be offered an additional \$10 to compensate them for participation in the Experimental group.

MEASURES: Physician measures: 1) Practitioner Perception of Patient 2) Caring attitudes (measure?) 3) (For experimental group only) Brief questionnaire on new information, insights after reading patient narrative. Patient measures: 1) SF-36 2) Symptom checklist 3) Satisfaction.

DATA ANALYSIS, POWER ANALYSIS and ANTICIPATED RESULTS: We expect this process to have two therapeutic effects as is true in the multiethnic population of this primary care clinic. Secondly, we expect physicians who read their patient’s stories to alter their perceptions and understandings of the patients based on this new

method of presentation. Therefore, we expect the act of reading their patients' stories will increase caring attitudes.

SIGNIFICANCE::

PERSONNEL: Johanna Shapiro, Ph.D., is a tenured full professor in the University of California Irvine Department of Family Medicine, where she has taught and done research for the past twenty years. Trained as a psychologist, her areas of expertise include family coping with illness and disability, and educational methodologies for teaching residents about psychosocial aspects of patient care. She has a longstanding interest in patient narrative, and has published several articles in this area.

Desiree Lie M.D., MS is an associate clinical professor in the UCI Department of Family Medicine. Dr. Lie is co-director of the first year Patient-Doctor course, and also directs the Egyptian Physician Family Medicine Training Program, which trains physicians from Egypt in the principles of family medicine.

BUDGET: Dr. Shapiro - 5% time; Dr. Lie - 5% time. Research assistant, 100% time. Patient payment - 200 subjects total @ \$10 = 2,000. HPR support

TIME-LINE: YEAR 1 Phase 1; Year 2 Phase 2. \$50,000 per year

