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Referral→No Referral→Team: Moving Toward (Ante)Narrative Medicine in Healthcare Organizations

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> Narrative medicine surprises us into realizing that health and illness, pain and suffering, aging, dying, birthing, functioning despite injury, making choices about our biological states are pivotal times in which we become who we are, discover who we are, accept who we are, rage or pleasure toward who we are. We clinicians come to respect the tremendous intimacy our practice affords us, the privilege of accompanying persons as they navigate life-defining experiences. We turn out to be in a position to give much more than we thought we would – not only in the technical and biological realms but in the deepest, most private, most consequential realms of being as well. (Charon "Narrative Medicine as Witness" 120)

Aptly labeling humans, *Homo Narrans*, Walter Fisher (1) captured the essence of social interaction in the term narrative. The capacity for storytelling and the influence of these storytelling performances to generate meaning is a uniquely human experience that can transform doctor-patient communication. Fisher's fruitful efforts to integrate the narrative paradigm into communication research is where I enter the picture some years later. My overlapping intrigue with organizing, narrative, and health care is the impetus for this work. The primary argument of this article is that: teamwork, in the contexts of intra and inter-organizational communication, fosters what Boje ("Stories of the Storytelling Organization" 999) and Barge (107) characterize as antenarrative storytelling in health care relationships. An argument for an antenarrative approach to narrative medicine is laid out using an autoethnographic account of my illness narrative. The rupture in my *normal* identity (Bruner 5) as healthy transpires in "referral → no referral → team" plot beginning in 2005 with my primary care physician, leading up to 2010 with a professor at a prominent research hospital, and culminating, but not ending, in 2012 with a team of doctors at two different university affiliated research hospitals.

Referral → No Referral

In 2005 at age 33, I began to experience progressive symptoms that seemed to be unrelated. It began with renal stones that required lithotripsy – an indescribably painful experience as most renal stone sufferers express. Unfortunately, my pain did not subside even after the stone passed. My pain related to renal stones concentrated in my right kidney, but chronic pain extended into my joints and muscles coupled with weekly migraine headaches making it difficult to concentrate, work at a computer desk, and perform other taken-for-granted daily activities. Additionally, I had chronic gastrointestinal problems and fatigue that remained undiagnosed. By 2008, my kidneys had formed stones again, and I experienced a small stress fracture below my right knee. To say that I was frustrated with my deteriorating health is putting it mildly. Nevertheless, one of the most respectable and enduring qualities of

my primary care physician is that he will refer you to other doctors without hesitation. During this time period, I was referred to a litany of specialists related to urology, rheumatology, and gastroenterology who tested me for Lupus, Rheumatoid Arthritis, Celiac disease, Krone's disease, Sjogren syndrome, diabetes, hyperthyroidism, hypothyroidism… Shall I continue? My aching body felt more likened to a test tube than a living being as I underwent blood tests, computed tomography (CT or CAT) scans, magnetic resonance imaging (MRI), urine collections, endoscopy, and colonoscopy.

If it were not for my family doctor's tenacity to piece together narrative strands from my patient history, ongoing clinical visits, test results, and specialists' notes, I might have given up. I do not believe my experiences to be extraordinary, but I do believe my experiences to be telling. With most referrals to specialists, I anticipated that his(er) expertise would provide answers, even if partial. Arthur Frank (*The Wounded Storyteller* 76) might classify this expectation as typical of restitution narratives – that is the narrative hoping for restoration of the pre-illness state. Optimism gave way to discouragement as I found that referral after referral became a circular pattern without answers. The urologist ordered his battery of tests. The rheumatologist ordered his battery of tests. The gastroenterologist ordered his battery of tests. In each scene, the follow up appointment's plot was similar. Specialists pronounced inconclusive medical evidence for my symptoms and claimed medical ignorance in attending to symptoms outside of their specialty. In each case, I came full circle back to my primary care physician, who seemed to be the only doctor concerned about my quality of life in relationship to my range of symptoms.

Rita Charon ("Narrative Medicine" 1897), author of seminal works in narrative medicine and Professor of Clinical Medicine at Columbia University, writes, "Sick people need physicians who can understand their diseases, treat their medical problems, and accompany them through their illnesses." This basic argument for the practice of narrative medicine is a resounding anthem in my health care experiences and surmises how I perceive my primary care physician to have accompanied me through the iterations of medical testing, uncertainty of diagnosis, referral after referral, and treatment after treatment. In an unexpected turn of events, renal stone production and low vitamin D levels prompted a bone density test. At age 38 I added osteoporosis to my litany of health problems. This time I asked my primary care physician for a referral to a doctor recommended by a rheumatologist at a university affiliated care center in a metropolitan area. Specializing in endocrinology, his work with mineral metabolism and males with osteoporosis was well published giving me hope that my cycle of disappointment would be shattered. The initial appointment affirmed this hope as he educated me on bone loss processes in males versus females and asked me about my symptoms. It was not until my follow-up appointment to discuss test results that disillusionment set in.

"Stop going to doctors. Relax," captures the advice my endocrinologist gave me in 2010 and is the mid-point in my referral → no referral → team experience with the medical profession engaging my health narrative over an eight-year period of uncertainty related to pain, renal stones, and osteoporosis. It was if my endocrinologist was making a proclamation to me of narrative closure on a story still in the making. Perceiving that he sincerely sympathized with my frustration with the outcomes of previous referrals, I, unwittingly, heeded his advice for a period. The quintessential problem with his advice was its *contextlessness*. If I was not in chronic pain, if I did not have reoccurring renal stones, if my bone loss was improving…, this advice would have been functional, but I, in effect, would need to

be a different person. During the "no referral" stage in my illness narrative, my primary care physician found this near impossible as I developed three herniated discs in my cervical and thoracic spine further complicating pain management and discovered 45 stones in each of my kidneys. To be clear, that is a total of 90 stones. At this juncture, my primary care physician compiled an application packet and my medical records to refer me to the head of internal medicine, Dr. Gallant, at a different university hospital, and this is the juncture that my experience with narrative medicine at the family practice level became antenarrative team-based storytelling at the research level.

No Referral → Team

In 2012 my first clinical encounter with Dr. Gallant was an hour-long precursor to an eight-month antenarrative spanning across team members, specialties, and health care organizations. Before delving too deeply into my personal antenarrative experience in a team context, clarity is needed in regard to how I am using the term antenarrative. David Boje ("Narrative Methods" 1) introduced the term antenarrative as an alternative to narrative in order to capture the fragmented and speculative nature of storytelling, the multiplicity of meanings gleaned from stories, and the elusiveness of narrative closure. The play, *Tamara*, serves as a metaphor for antenarrative. A popular and long-running play in L.A., *Tamara* unfolds on multiples stages simultaneously as audience members chase plot lines through the corridors and rooms of the home that functions as its playhouse. Audiences often see the play multiple times in order to see different fragments than the time before. Once more, *Tamara's* characters keep audiences on their toes with unexpected twists in characterization and plot. Boje ("Stories" 999) uses *Tamara* to illustrate organizational storytelling and the storytelling organization. Kevin Barge's (121-122) work with antenarrative explored its relevance to managerial practices and extended its reach through the concept *systemic storytelling* that moved beyond description to prescriptively helping managers make sense of organizational experience, remain curious and speculative about narrative possibility and meaning, and develop resources for constructive change. Antenarrative and systemic storytelling are intriguing constructs within the narrative paradigm that offer both descriptive and prescriptive possibility to narrative medicine, which signals me to return to my narrative in order to demonstrate these possibilities.

In three months Dr. Gallant had a rheumatologist, geneticist, and a nephrologist consulting on my case. The rheumatologist entered the scene early on as a colleague who shared patient rooms and administrative staff with Dr. Gallant. Shortly after my first meeting with Dr. Gallant, he put me in contact with a geneticist at a different medical research hospital that he knew through a bone club that met monthly and through intersecting research projects. Dr. Gallant hypothesized that genomic sequencing might shed light on a singular cause for my pain, bone loss, renal stones, and herniated discs. The last team member to enter the picture was a nephrologist referred to me by the geneticist, whose input on renal stone production and prevention was desired.

This cast of highly respected medical researchers and practitioners each have their own areas of expertise and each invited me into conversation by drawing out my illness narrative – my desires for restitution, my suffering through pain, and my search for causes, not just treatment. But, rather than operating in silos, this unlikely dream team added storylines and speculated possibilities within their respective health care organizations and across organizations. No, they did not call a team meeting with a white board to find the perfect

diagnostic test or a rare disorder to explain my health status. Interactive, ongoing storytelling has transpired and accumulated through bone club meetings, phone consultations, faxed notations and test results, and patient consultations. While this fragmented, unstable, and organic communicative process is not taking place in the traditional corridors and offices of a storytelling organization, this team-based approach to my case is indicative of a storytelling culture, a commitment to the patient's perspective in storytelling, systemic storytelling within and across health care organizations, and acceptance of multiple narrative voices and narrative speculation.

There is no "resolved" stamp that can seal my medical files. My dream team may or may not be educated in narrative medicine principles and techniques as I have not inquired. Nevertheless, they are undoubtedly analogous to the cast of *Tamara* as they are performing on different stages in the same drama, exploring multiple narrative possibilities, and ensuring that I, the patient, am not an audience member in my own drama (Boje "The Storytelling Organization" 106-108). The process of referrals emanating from my primary care physician has been an ebb and flow of promise and discouragement. However, the experiment in no referrals proved an unrealistic plot for my story. From this I have learned that not just any assemblage of medical experts can constitute a team, but that a team embedded in a culture of storytelling whose expectations of one another is that they will be responsible for their fragment of the story can integrate antenarrative and narrative medicine together artfully.

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