# An Autoethnographic View of Health Care through the Lens of Relationship Management Theory

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#### Introduction

It was December 23, 2008 and my mother was in the hospital waiting to hear if there was a viable procedure to help her. You see she had fractured several thoracic vertebrae in her back and had been and was enduring an intense amount of pain. The orthopedic surgeon suggested a procedure called vertebroplasty. This is a minimally invasive procedure where a type of cement is injected into the vertebrae bodies with the goal of holding the vertebrae in place until it heals on its own.

My Mother was not a candidate for major surgery because narcotics and anesthetics depressed her breathing and cognitive functioning. The vertebroplasty was performed. On January 5, 2009 a nephrologist, who we had never seen before, visited and said that Mother had 33% kidney functioning. She immediately followed up saying that Mother could go home.

My Mother was 89 years old at the time of this hospitalization. My brother, Paul, Mother and I all thought it was normal for the kidneys of an 89-year old woman to function at this level. No alarm was raised, no note of concern was discussed about the level of her kidney functioning, and no hint of possible future trouble was announced. The nephrologist simply made a factual statement and then a discussion of leaving the hospital ensued.

When we discovered the vertebroplasty did not work and Mother's back pain grew worse, the doctors prescribed Darvocet. This is a drug that we later discovered should not be given to patients with renal insufficiency. It is also a drug that caused electrical inefficiency in the heart and decreased respiratory functioning.

Within three weeks of taking Darvocet, my Mother went into renal failure and was placed on dialysis in October 2009. Within one year of being placed on dialysis she had to have a pacemaker. One year after that Mother went into respiratory distress. On July 11, 2011 Mother was put a ventilator. On August 12, 2011 Paul and I decided Mother needed a tracheotomy and peg tube for feeding inserted in order for her to survive.

I should explain. My Father died when I was three, Paul was seven and my other two siblings were 12 and 14 respectively. My Mother raised two young children and two teenagers by herself. Let me add that my Father died in June, my maternal grandmother (who lived with us) died in July and my maternal grandfather (who lived with us) died in January. You can see my Mother (and older siblings) did not have an easy time. She was a tenacious Southern lady who loved deeply and completely and gave of herself fully.

Fictional names are used to protect the privacy of all individuals mentioned in this article.

Mother, Paul and I have always been very close. Mother taught us that the only person you can and should absolutely count on is your family. The unit of people who comprise your family is sacred. Family comes first --- no ifs, ands, or buts. We talk about everything and are there for each other through thick and thin.

Mother cherished life and told us when she became ill (toward the end of her life) we MUST do everything possible to help her live. Mother was currently in a situation where she had a fully functioning mind, but due to being bed ridden for months she was totally de-conditioned and unable to move her limbs without help. She could not talk because of the tracheotomy. Paul and I discussed all decisions with Mother and we tried to read her nonverbals and mouth movements, but we became her voice. The introduction is an excerpt from my personal account of my experiences in hospital settings with my Mother while she struggled to recover from respiratory and renal difficulties.

Living through over four years of hospital stays and observing the internal and external operations of the healthcare providers with patients and their families I knew I had to find a venue to disseminate the rich knowledge I gained. After sifting through the various theories and methodologies available to a social scientific researcher I decided that my observations were best supported by health communication and relationship management literature and framed by the methodology of autoethnography.

# Autoethnography as Methodology

Autoethnology is a form of research that uses the researchers' own personal stories and experiences as a topic of investigation (Porter, 2004). Describing the personal stories helps others understand cultural experiences. Ellis (2004), Hollman-Jones (2005), Spry (2001), Adams and Hollman Jones (2008) state that autoethnography is a methodology that is politically and socially just. Ellis, Adams and Bochner (2011) add that is both a process and product.

This method is used to better understand culture and cultural methods and practices. That is the values, beliefs and experiences of those in a designated culture such as health care. The shared purpose of those inside the health care system are referred to as cultural insiders and those seeking to understand the culture such as patients and their families are called cultural strangers. The autoethnographer selectively writes and analyzes the epiphanies that stem from being a part of that culture and/or by possessing a particular cultural identity. (Ellis, Adam, Bochner (2011). The writings come from field notes, artifacts and perhaps interviews.

There are various types of autoethnographic procedures. The one used in this study most closely adheres to the layered account where the researcher's observations and experiences are discussed and measured against abstract analysis and relevant literature. This type of research frames the analysis and observations into questions and comparisons rather than an absolute truth. This account used vignettes to tell a story and led readers into a culture and, hopefully, into their introspective view of that culture and formation of their own value through an emergent process of narrative and literature (Ellis, 1991; Ronai, 1992; Rambo, 2005).

The criticism of autoethnography is that of reliability, generalizability and validity. How can writing a personal story be systematic, scientific research? Bochner (1994) and Denzin (1989) state that researchers who use this method value narrative truth based on what a story of experience does --- meaning, how it is used, understood and responded to by others. Owen et al (2009) also recognize that people tell the same story in different terms and remember it in different ways. Therefore, validity, reliability and generalizability as applied to this method are altered.

Reliability in autoethnography is referred to as the narrator's credibility. Bochner (2002, pg. 86) asks the following questions to determine credibility: "Could the narrator have had the experiences described, given available "factual evidence"? Does the narrator believe that this is actually what happened to her or him? (Bochner, 2002, p.86) Has the narrator taken "literary license" to the point that the story is better viewed as fiction than a truthful account?"

Validity is described in this method as believable. Is it possible that the narrative is true? Of course, the story must connect the reader to the writer and help him/her understand the experience described. The goal is for the story to help improve the lives of the readers or at least provoke a way of thinking. The story needs to be useful in some way (Plummer, 2001).

Generalizability is defined differently in autoethnography than it is in social science research in that it does not apply to large random samples of subjects. In this method "generalizability moves from respondents to readers, and is always being tested by readers as they determine if a story speaks to them about their experience or about the lives of others they know; it is determined by whether the (specific) autoethnographer is able to illuminate (general) unfamiliar cultural processes (Ellis & Bochner, 2000; Ellis & Ellingson, 2000)." Readers compare their stories to ours and identify the similar and contrast the different. They analyze the stories for what they have learned and seek out the familiar and unfamiliar (Flick, 2010).

Autoethnography is criticized for not being rigorous research. Hollman Jones (2005, p. 764) addressed this very eloquently saying, "Autoethnographers view research and writing as socially-just acts; rather than a preoccupation with accuracy, the goal is to produce analytical, accessible texts that change us and the world we live in for the better."

### Health Communication and Autoethnography

Health communication has been conducted for over 30 years and a list of new studies is being added on a daily basis. Healthcare providers and patients all agree that communication is a vital component to a successful relationship between the two parties. Cegala and Broz (2003) analyzed studies looking at health care provider communication skills and concluded that there is a "lack of coherence and focus in the literature (pg. 96)." They state that the studies lack a consistency in defining what constitutes a communication skill in health care and/or among health care providers. Cegala and Broz go on to say that "little information is reported on what is taught and when it is reported (pg. 96)."

In my observations I found this to be true.My Mother was to receive a dose of medicine. A nurse came in and gave it to her. Four minutes later a different nurse came in to give Mother some medicine. I asked what she was giving her. The nurse, not use to answering questions such as this, reluctantly answered me. It was the same medicine Mother was just given. I informed this nurse that Mother had just received that medication. She asked if I was sure. I answered that I was. She asked who gave it to her. I told her the name of the nurse. She left seemingly unhappy with me. I did not care about the attitude of the nurse that evening because I saved Mother from receiving an overdose of medication!

On another evening Mother was in pain with her back. The doctors wanted to give her a narcotic to ease the pain and recommended Morphine. This is yet another drug that depresses respiratory function. Paul and I said NO. We were assured the doctor would find a non-narcotic for her. An hour and half later pharmacy sent up pain medicine for Mother. Paul had gone home and I was staying the night. Fortunately it was summer so I was at the hospital full-time. I was on night 40 of this hospitalization. Coming out of the restroom I noticed they had given Mother medicine. I asked what it was. They responded that it was Morphine. My head went into a black hole of fury. My mouth said, "No, Mother cannot have a narcotic. She is allergic to it. Back it and back it out now." I asked to speak to the house doctor since it was nighttime. Mother still needed pain medicine. Of course, the medicine was backed out and my "request" was reported to the on-call doctor and attending doctor before I could talk to them. I immediately called Paul and told him what I had happened. He was furious at the circumstances and thanked me. I asked Paul to return to the hospital so we could present a united front to the house doctor. The house doctor was not happy we had countermanded the order. We had to explain, once again, the extreme reactions Mother had to narcotics. The house doctor said reactions to narcotics should be noted in her chart. We responded that the reactions to narcotics and anesthetics appeared when Mother had a procedure to repair a fractured hip, so they are clearly noted in her chart. He checked Mother's chart and the information about the narcotics were highlighted. Obviously the previous doctor and nurses did not read Mother's chart.

The attending doctor did not carry through on the agreed upon medication nor did he communicate it properly to the nurse. We addressed our concerns with the house doctor who prescribed a different medication and then the next day we explained the situation to the attending doctor. We asked why he did not prescribe the non-narcotic. He said he forgot since he deals with so many patients. Paul and I visited the nursing supervisor and requested another "attending" immediately.

A study conducted by Tay, Hegney and DNurs (2011) found that nurses who appeared genuine, competent and skilled communicators elicited more trust from their patients then nurses who were task-oriented, exhibited low self-awareness and showed a fear of death.

The results of Tay et al's study suggest that nurses who provide accurate and supportive communication and who know how to facilitate patient disclosure can promote communication. In addition, patients trust competent nurses better and share more feelings with nurses who treat them with genuine care and concern.

After being at the hospital days and nights on end, Paul and I quickly learned that we had to watch everything that was said and done for and to Mother even though she was in an ICU at the time. The evening before Mother was to have a peg tube implanted that day nurse told me Mother would be NPO (nothing by mouth) from midnight until the procedure was completed. At the time Mother was on a continuous feed. I was grateful for the information because her nutrition is of utmost importance since she is a renal patient. However, she needed this procedure. It just so happened that at midnight I forgot to remind the night nurse to stop the feeding. At 3 a.m. I looked at the clock and remembered that the feed was still running. I contacted the nurse and told him the feed had to be stopped. He said to me that Mother was NPO all the time. I looked at him strangely and said no that was not correct. She was on a continuous feed. He said he would look at the chart.

Since this same nurse had Mother the night before I did not understand why he was so confused. He did not stop the feed until 5 a.m. Mother's 8 a.m. procedure was cancelled due to the nurse's error. The nurse was too focused on other tasks and did not effectively communicate with me to perform his duties for my Mother.

Another finding of Tay et al (2011, p.157) is patients who initiate conversation in order to collect health information or to take part in their own care can promote nurse—patient communication. In my observations I found this to be both true and false. It depended on the hospital floor environment and the nurse.

Nurses are assigned to a patient based on the number of days the person works in succession. If a person works two days in a row, then that nurse may be with a patient for those two days before someone else is rotated into that slot. Paul and I rejoiced when Mother was assigned the friendly, competent nurses. We felt more at ease on those days. The tension filled the air on days when the nurses who projected a sense of entitlement, laissez-faire or roughness were on duty. Many nurses did not appreciate the family's continual presence, especially when we questioned everything about Mother's care. Now Paul and I were never rude or dismissive with questions, but we did want answers. Also, we never left Mother alone, not even when they changed her. In fact, we learned to change, lift, suction, bathe and feed her, so we could help the nursing staff. Many nurses, however, felt this to be inappropriate. We said, why? We do it at home. They thought we were checking up on them. Well, no. We know the way to handle Mother so her back is cradled and not hurt any further. We know how to suction her so it is gentle and does not hurt her as much. And, yes we do not want her to receive something she does not need, such as an overdose.

One Tuesday night I refused to leave while the nurse did her initial check of her patient, Mother. She said she believed in patient confidentiality more than anything. Mother was on the ventilator at the time. I told her there was nothing confidential that I would have to supply any information she needed. She argued with me. I told her I was given permission to stay and I was not leaving. She told me that she had the right to ask me to leave at that time because confidentiality was important. My Mother was fighting to breathe and here this nurse was arguing with me, so I simply said that she should be more concerned with patient care than confidentiality. It was midnight at this point. I called Paul and he called the night supervisor and talked to her. The supervisor talked with the nurse but never with me. The rest of the night and following morning were tension filled. The nurse slammed every door and drawer in anger. This upset Mother and I was filled with tension. It was a great relief to me when Paul returned the next day. It was like an army of support coming as backup for Mother and me.

A more pleasant nursing experience was when I advocated for a holistic treatment to eliminate a blood blister on Mother's leg. Many renal patients' experience dry skin and blood blisters. If they are not treated immediately and with the utmost care infection can set in if the blister bursts. I had heard of using emu oil on dry skin so I started rubbing it on Mother's body. When the blister appeared I immediately rubbed it in. The wound care nurse had another treatment prescribed, but one of Mother's more regular nurses talked to the attending and encouraged him to let me try the emu oil. He agreed. The emu oil worked and he started using the oil himself.

Sawatzky and Fowler-Kerry (2003) said that to adequately care for a chronically ill patient on a long-term basis a stable grouping of caregivers is needed. They describe the care giving experience as life changing and consuming. Sawatzky and Fowler-Kerry (2003) go on to say that "the domain of care giving could be captured by three dominant themes: loss and grieving; adapting and coping; and the short- and long-term impact (p.279)."

Family caregivers enable the economic cost to the U.S. health care and long-term services and supports (LTSS) systems to remain at the level we see today rather than a much, much higher one. It is determined that in 2009 the economic contributions of caregivers were \$450 billion. An estimate for their value in 2012 has yet to be determined (Feinburg, Houser and Choula, 2011).

Feinburg et al (2011, pg.3) define \$450 million by saying:

- "How Much is \$450 billion?
- -More than total Medicaid spending in 2009, including both federal and state contributions for both health care ad LTSS (\$361 billion)
- -Nearly 4 times Medicaid LTSS spending in 2009 (\$119 billion)
- -More than twice total paid LTSS, regardless of payer source (203 billion in 2009)

- As much as the total sales of the world's largest companies, including Walmart (\$408 million in 2009, the most of any company) and the three largest publicly held auto companies combined (Toyota, Ford, and Daimler: total \$439 billion)
- Approaching total expenditures for the Medicare program (\$509 million in 2009)
- -Almost \$1500 for every person in the United States (307 million people as of July 1, 2009)
- -About 3.2 percent of the U.S. gross domestic product (\$14.1 trillion in 2009)."

Family caregivers supplement the care provided to the patient by direct caregivers. The family care is given often out of financial need, value system or cultural norm. Whatever the reason there is a growing recognition of the value of the family members delivery of care to the health care system and the long-term services and support systems. Families can influence health care decisions, treatment, and outcomes (Feinburg et al, 2011).

It began as any other night except Mother had just been transferred from the INCU (Intermediate Intensive Care Unit) to a MedSurg floor. She had been on a ventilator then weaned off if it. She was breathing normally. Paul and I thought she should have remained on the INCU floor because Mother would be on a 4- hour schedule for visits from a respiratory therapist. A pulmonologist had not been to visit her all day. As it neared 8:30 p.m., Paul noticed Mother was breathing irregularly. Her breathing began getting faster and faster. A person usually has10-12 breathes per minute. Mother was breathing 40, then 50, and 55. We went to call a nurse... a doctor.... anyone who would help. Finally a nurse came. A rapid response team was called. The team leader wanted to immediately intubate Mother. Paul wanted the house doctor called. Mother's breaths numbered 65 now. I asked them to bag her. The rapid response team nurse did not want to do so. The house doctor said to bag her for now. The team was trying to tell us to intubate or let her go. Paul and I were not about to let Mother go, She wanted to live and we were going to see that she lived. I wanted to give Mother a chance to breathe off the ventilator. We talked to the house doctor and he said the rapid response team should continue to bag Mother and if her blood gases came back good then we could keep her off the ventilator and place her on a C-PAP machine for the night. The nurse in charge of the rapid response told me I was being cruel to Mother. She would not let her suffer like that. I responded that she did not know my Mother, her medical history or her wishes.

Mother's blood gas came back in the good range. The house doctor said it was a good call. She remained on the C-Pap machine for the next couple of nights and then was free of the C-Pap machine and the ventilator.

From my experience even though family caregivers are needed, the direct caregivers often resent the decisions they make. However, the decisions made for the patient are influenced when the family caregivers are present. My best advice to all who love their sick family members is be present at all times so you can help make an informed decisions. Do not allow the professional caregiver to make the decisions without your consultation

#### As for costs...

I remember many days where nurses on different floors were assigned to the INCU, where Mother was assigned, due to a shortage of nurses. Mother was always assigned a floating nurse rather than a floor nurse. She had been in the hospital so long insurance was no longer paying the higher premium so they assigned "whoever." Also, the floor nurses did not like putting up with "the family watching over them." I overheard the nurses saying this. The nurses who knew us realized we helped change, feed and exercise Mother. And yes, we did monitor the medication given, blood pressure, pulse ox, suctioning, and all suggested procedures and tests. We also asked questions. We wanted only the best medical care for our Mother. We wanted her to live and live a good life.

Foster, McAllister, and O'Brien (2006) posit that the "self" is connected to the social world and is in a constant state of flux. The "self" is that which creates a social exchange and integrates into a relationship (Bohan, 2002). This concept applies to the nurse-patient relationship in that there is an interdependent interrelationship between the two people, according to Foster et al (2006, pg. 45). If the nurse exhibits positive characteristics to the patient then it is possible the patient and, by extension, the family, may construct positive a more pleasurable experience or outlook.

Each morning as 7a.m. approached and the change of shift occurred I prayed that Mother would be assigned specific nurses. We wanted a nurse who was friendly, competent, gentle and made Mother smile. The days when a nurse who was not friendly or competent or gentle was assigned to Mother was a day filled with terror. The same horror filled my being when I saw the respiratory therapist for the day. Just imagine a suction tube going down your throat multiple times a day cutting off your airways. Mother made an awful face each and every time she was suctioned. It was horrendous to watch and even worse (if imagine) to experience.

The therapists and nurses who were gentle gave Mother oxygen before and after they suctioned her to reduce the acute pain. Others nurses and therapists performing this function did not care. They were quick and did not care how it affected Mother. Except for five of the nurses and respiratory therapists (in a year's time), these professional health providers constructed a very traumatic outcome for Paul and me in relation to respiratory suctioning.

I walked into Mother's room one morning and Mother was choking. She needed to be suctioned. The nurse was trying to suction her, but could not effectively get the tube down her throat. She kept pushing and pushing at the shiley inserted into Mother's throat. When you push onto the shiley it causes a great deal of pain to the patient. Push onto your own Adam's Apple and you will feel 1/64<sup>th</sup> the amount of pain the patient feels. I told the nurse the tubing she was using needed to be twisted for it to go down. She ignored me. Seeing my Mother's face in agony I went to the nurse's station and found my favorite nurse and said "Carol, please come quick. Mother is choking and the other nurse cannot seem to suction her." Carol came immediately. To save face she suggested to the nurse she needed different tubing. While the other nurse was gone, Carol twisted the tubing and successfully suctioned Mother. By this time I was shaking and traumatized. Mother was red-faced and her pulse-ox had dropped dramatically. If only the original nurse had listened to me Mother would have been spared this needless suffering.

A nurse or therapist can bring out a variety of "selves," depending on the relationship with the patient. It is the nature of that relationship which allows different characteristics to blossom (Foster, McAllister, O'Brien, 2006).

All of her life my Mother has been a flirt. She loves to harmlessly flirt with men, no matter their age or hers. Continually she has told me that she did not put blinders on when she married. Now my father died when I was three-years old. She promised him she would never remarry, (and she never did) but she never said anything about looking and flirting! She thinks I am a prude and need to loosen up. Perhaps I do. Even as chronically ill as she is in the hospital and unable to verbally communicate she flirted with the physical therapist. To the best of her ability she straightened her body and smiled at Kim (the physical therapist) and let him work with her severely de-conditioned limbs and body. Kim had a pleasant personality. He talked directly to Mother and smiled at her. He was also gentle with her. I asked Mother if she thought he was cute and she indicated that she did. Kim's characteristics constructed a difference, more pleasant, experience for Mother, if only for a short time.

### Health Care Communication Conclusion

Studies found that effective communication skills of direct health care providers is important to patients and their families, especially when giving information. Genuine competent and skilled communicators who are nurses, therapists and/or doctors elicit trust between and among patients and family members.

In 2009 family caregivers services in the United States were valued at \$450 billion. Family caregivers lower the cost of health care. Today, 46% of adults in the United States are family caregivers, according to the National Health Policy Forum.

The construct of the "self" shapes reality for the individual, so nurses can help the patient construct a positive experience.

Usually on the weekends Mother was assigned to a nurse who only worked weekends.... Carol. Carol was middle-aged, working on a Masters Degree, hated the gossip of the floor, and concentrated only on her patients. When you called her she came immediately. She laughed and joked with her patients and joked with the patient's family. She actually talked to Mother, even though she could not talk back. Carol encouraged us to help care for Mother. In fact, she gave us jobs, which made us feel useful to Mother. We felt Mother was safe with Carol. In fact, Paul and I looked forward to the weekends.

### Relationship Management Theory and Autoethnography

Ledingham and Bruning (1998) viewed public relations from a relational perspective—that is a "management function that uses communication strategically" (p. 56). Bruning and Ledingham (2000) explained that the relational management perspective moves public relations practice away from "manipulating public opinion through communication messages" to a combination of "symbolic communication messages and organizational behaviors to initiate, nurture, and maintain mutually beneficial organization-public relationships" (p. 87).

Ledingham and Bruning (1998) defined organization-public relationships as "the state that exists between an organization and its key publics that provides economic, social, political, and/or cultural benefits to all parties involved, and is characterized by mutual positive regard" (p. 62). This definition of relationships is quite narrow in that it excludes negative relationships that can develop. Hon and Grunig (1999) explained that an organization-public relationship occurs when a possibility of consequences occurring exists.

In any relationship there is the possibility of negative experiences if the communication messages and organizational or public behaviors do not nurture the relationship. In my observations of the off site dialysis and hospital settings the lack of nurturing and contracted behaviors led to negative organizational imaging and near death consequences for my Mother.

In October 2010 Mother was released from the hospital. Paul and I elatedly brought her home. Before leaving the hospital Paul, as the primary care giver, was trained to suction Mother. He was also trained to operate the feeding machine so that Mother could be fed through her peg tube. We rented a hoist machine to move Mother from the bed to the couch so she could sit upright. We also had to learn to operate the machines to give Mother oxygen. In addition we had to arrange for out patient dialysis at a center that could handle a tracheotomy patient. This is not an easy task, but we found one center in the entire South Jersey area. Finally, we hired a private duty nurse (who was a former ICU nurse) to help care for Mother at home.

Mother received dialysis three days a week for four hours a session. We took Mother by ambulance to dialysis. Paul's house is at the top of a steep incline. The only way to reach the entryway is by many stairs. Mother has always been frightened of going in and out of the house by wheelchair or stretcher because of the steep incline and stairs. She felt she might be dropped. Do I need to say that Mother also hated dialysis itself? Given these conditions dialysis day was filled with tension.

The first dialysis session after being discharged from the hospital was a Friday. When we arrived at the center the director welcomed us and assured us that Mother would be in good hands. I stayed with Mother during the treatment. About two hours into the treatment Mother began choking. Neither a dialysis nurse nor technician was to be found. I went in search of someone to notify him or her that Mother was in distress. A nurse came, assessed the situation and went to find a suction machine. The nurse brought a suction machine and it did not work. Mother was still choking. She went in search of another machine and brought it back. It did not work. Another nurse found a third suctioning machine and it finally worked. Mother started to breathe normally. This entire episode took 25 minutes!

On the following Monday Paul took Mother's suction and oxygen machines to the dialysis center when Mother for her treatment. He also took Mother's private duty nurse. When they arrived at the center, Paul set up the equipment, made sure everything worked. Lorane, the private duty nurse, was in place in case Mother needed suctioning. Paul left. The director at the center told Lorane that she could not stay with Mother. She could only see her 15 minutes every hour. (This is a departure from Friday when I stayed the entire Paul with Mother). At the designated 15 minutes Lorane went to see Mother. She was cyanotic. She could not breathe at all. The nurse watching her said, "Oh, she is okay. Look at her numbers. Lorane responded, "She is blue and not breathing, call an ambulance, NOW." Lorane started bagging Mother. The ambulance arrived and Mother returned a hospital. Lorane saved her life.

We reported the incident to the County's Department of Health. The incident was investigated by the County and then reported to the State's Department of Health. The dialysis center was cited for improper care, cited for negligence and heavily fined. This center can no longer accept respiratory patients.

The dialysis center's lack of nurturing created negative imagining for the organization among its patients and the county and state health departments.

Many researchers have put effort into developing relationship constructs. Broom, Casey, and Ritchey (1997) suggested relationship concepts, antecedents of relationships, and consequences of relationships in their three-stage model of relationships. Bruning and Ledingham (1998) surveyed literature in interpersonal communication and social psychology and identified five dimensions of relationships: trust, openness, understanding, involvement, and commitment. Ledingham and Bruning (1998,) operationalized the relational elements in the following ways:

1. Trust: a belief in disclosures—"I believe in what he or she says and/or does."

- 2. Openness: making an effort to be open about themselves to the public
- 3. Understanding: wanting the public to understand him or her and his or her behaviors
- 4. Involvement: being aware of the organization and its people and wanting to be involved with the problems and problems-solving process for the organization and its patients
- 5. Commitment: being dedicated to the health and welfare of the organization and its patients.

In reviewing relationship management studies, trust appears to be a vital factor. Trust is described by Leichty and Springton (1993) as "a small risk by disclosing personal information . . . If the other party reciprocates the self-disclosure, then the first party is likely to self-disclose again . . . and mutual trust emerges from a positive feedback spiral" (pp. 180–188). Leichty and Springton (1993) stated that this process is similar for an organization and its various publics.

Grunig (1993) noted that these behavioral concepts referred to by Leichty and Springton (1993) are endemic to interpersonal communication. The measures of trust, openness, understanding, commitment, and involvement can be used to measure the quality of behavioral relationships of organizations. Ledingham and Bruning (1998) said that these measures could also engender loyalty toward an organization among key publics when key publics know that involvement.

In my observations these relational elements placed the organizations we dealt with in positive and negative lights.

Trust, one of these relational elements, is defined as a person or organization's confidence or willingness to confide in another person or public.

#### **Pro-Trust**

Mother's cardiologist, Dr. S, was not only a heart specialist he was also trained in nephrology. He is a smart and reliable man. Whenever you are a patient he gives you his cell phone so when you call him you get him and not an answering machine or secretary. Whenever we called, Dr. S answered and came to Mother immediately. We asked Dr. S renal questions and he either told us the answers or questions to ask. Mother liked and trusted Dr. S because he was respectful and truthful. Even after Mother's pacemaker was implanted and her heart was stable, we called on Dr. S because we trusted him.

#### **Anti-Trust**

One of the hospital nurses in the INCU, Jenni, was nice to Mother. Whenever she was with Mother she tried to meet her needs. Jenni was not the most gentle of nurses, but she was adequate. She did talk to Mother some. Mother did not respond to Jenni, which said a lot to me because Mother was so perceptive about people. One afternoon after dialysis Mother's heart rate increased rapidly due to improper access of her dialysis catheter. Jenni had drawn blood drawn from the catheter instead of accessing a vein. The site was infected as a result. Normally no one but a dialysis nurse is to touch the catheter. The attending physician told Jenni to change the catheter dressing. She stormed out of the room to secure the appropriate supplies saying, "Why are we bothering doing this, she is brain dead anyway?" Mother was functioning at a high cognitive level, so her statement hurt me deeply. Fortunately Mother did not hear her, but she watched her actions.

Mother's reactions to Jenni were right. Jenni's behavior toward her was not genuine. Mother never looked at her again. Frankly, I had a hard time speaking to her after that afternoon. I certainly never trusted her again.

When numerous and in such an intimate setting such as healthcare negative observations and experiences over shadow positive ones.

Another relational element is openness and is defined as disclosing thoughts and feelings among all persons/publics involved in the communication or situation.

### **Anti-Openness**

Perma-catheters are prone to clogging. Once that occurs a medicine can be injected into it and left to set between dialysis sessions. If the clog is clear, then it catheter is good to go. If the clog is still present or if the flow is slow then the catheter needs to be changed. Mother's catheter did clog and it was changed to a site on the left side of her neck. The placement of the catheter was awkward because it was at the fold of the neck so it was to be a temporary site. After six weeks the attending doctor said the catheter would be changed, but the procedure was never scheduled. When asked about changing the catheter the nephrologists said that it needed to be changed.

The attending physician said no it should not be changed. We went on like this for two weeks. The attending physician then said that the current catheter would remain until Mother was ready to be discharged and then a permanent one would be inserted on the left side. One week later after a 4-hour dialysis session Mother was resting. (Dialysis takes a lot of energy and stamina out of the most robust patient, let alone a de-conditioned one like Mother.) A nurse comes in to tell me that Mother was going to have a new catheter inserted. I incredulously responded. "What do you mean? She is not suppose to have this procedure until she is discharged. Besides, she just had dialysis and she is depleted." I insisted on talking to the doctor. Upon speaking with the attending doctor I learned the nephrologists wanted the catheter changed. I called Paul. He and I decided that Mother would be better served to have this procedure on a non-dialysis day.

This lack of transparency about the timing of healthcare procedures created an image of doctors doing what they want, when they wanted without the permission of the patient or their family. This lack of openness may make the public suspicious about healthcare and healthcare providers

As we grew up Mother made us promise that if she ever went to a hospital that we would never leave her alone. She did not trust doctors or healthcare workers. Paul and I promised we would not ever leave her alone and we never did. This promise was not easy to keep, however. Hospitals do not like families to stay in a patient's room 24/7. We had to plead and cajole with administrators to allow us to stay past visiting hours. We had to make sure Mother always had a private room so that a roommate would not mind a family member being in the room. We are not noisy people, but another person makes a small room crowded.

Once Mother's white count soared to 35 she had to be admitted to the ICU. I was in Iowa at the time teaching, so he called me to come back to New Jersey. In the meantime, Paul told the doctor that he must speak with the ICU and make arrangements for us to be with Mother 24/7. The doctor did so. I arrived shortly after Mother was admitted to the ICU.

As soon as visiting hours were over. They wanted us to leave. Paul said no that the doctor had made arrangements for us to stay. The ICU supervisor said no that we could only stay during the day. Paul said that was not the arrangement. Mother cannot communicate due to the tracheotomy and one of us had to be with her at all times. A verbal battle ensued. It ended saying that one family member could stay the night, but only one family member could be there except during visiting hours, which started at 11a.m.

The private duty nurse came to see Mother and the nurse and supervisor reprimanded me saying that either she or I had to leave. It was unacceptable for both of us to be in the room. The private duty nurse is a licensed ICU R.N. who was given permission to stay with Mother by the hospital attorney. Both the nurse and supervisor were so angry that Lorane was in the room I asked her to leave.

The change in agreement and the hostility of the ICU nurses images this hospital as one that patients want to stay away from. In talking with nurses on other floors they found the ICU nurses to hold an attitude of entitlement and superiority. Patients are not given the care, nurturing or time that they were given on floors where nurses have a higher patient load. On the hospital's web site they state, "Our goal is to provide patient-centered care that's tailored to each individual's needs." This goal was not met in Mother's case since she needed her two children with her 24/7 without argument.

### **Pro-Openness**

In my experience chronically ill people need special attention in addition to special care. They need people to make over them, talk to them and pamper them. In a hospital setting the people to do this include family members, doctors (to a limited extent), technicians, therapists and nurses. One nurse who worked on the ninth floor was named Marya was from Venezuela. She was older than most of the other nurses and only worked on Saturday and Sunday. Every time she entered the Mother's room she would go straight to Mother and say, "Hello Pretty Blue Eyes. How are you today?" She would then proceed to ask Mother how she felt, tell her what she needed to do. Then the two of them would have a conversation. Marya would tell Mother about her children, or about what she did on her days off, or what she did at her church or, most importantly how great she thought Paul and I are! In turn we told Marya many stories about Mother and her love for life. Marya treated Mother as the fully functioning woman as she was.

Often either Paul of I would search for Marya whenever we needed something for Mother. She would response as fast as she could. She was open and honest when answering our questions.

If she did not know the answers to our queries she would find out for us. Mother smiled when Marya was around her. She did not stay on the ninth floor too long, but we always returned to see Marya and she came to see Mother whatever floor she was on.

The hospital stay had given the three of us many negative experiences of nurses. The self- disclosure and openness of Marya refreshed our belief in the fundamental philosophy of Florence Nightingale: a nurse loyally devotes his/her welfare to those committed to his/her care.

Understanding is a third relational element, which stresses that all communicating parties must have a mutual understanding of the message disseminated.

## **Anti-Understanding**

Contrary to conventional standards and medical wishes Mother, Paul, and I do not believe in Living Wills. Mother told us she wanted to live. Paul and I were determined to fulfill this wish. It is procedure for medical personnel to ask about a Living Will upon entry into a hospital. It, perhaps, is a procedure an attending doctor is required to inquire the first time s/he meets a patient, but we were continually encouraged to write a Living Will for Mother. We kindly declined. We were asked if we wanted a DNR for Mother and we declined. They questioned our judgment. The medical personnel tried to change our minds. We had planned our strategy and did not need to be questioned.

Mother was a small fragile woman. If aggressive CPR were performed on her most of her ribs and chest would be broken. We knew that this was not what Mother or we wanted, but if we signed a DNR, then the medical team may not do everything possible to keep her alive. One of us was always with her so we would give the directive personally. The medical personnel did not need to know our plan, but they refused to listen to our decision.

It was evident to the medical personnel that Mother, Paul and I were intelligent and knew we made informed decisions, so we resented their seeming lack of understanding of our informed decision making process. The continued pressure of this inquiry over the course of Mother's hospitalization intensified the extreme tension we were already experiencing.

Once reported to relevant publics this deliberate lack of understanding may appear to be harassment on the part of the hospital personnel.

### **Pro-Understanding**

Paul and I were determined that Mother would receive the best care possible, so we questioned every procedure, medication, and protocol that the doctors and nurses wanted to perform. First, we wanted to understand what they were doing and why and secondly we wanted to make sure it was not counter-indicated with her medical history. Paul and I carefully explained to the healthcare providers that we were concerned that Mother's history was being considered and that we truly wanted and needed to understand what was being done to and for our Mother. We were deliberately respectful and polite. Most of the healthcare providers were resentful of our inquiries and clearly told us that we were interfering with medical practices. We were told we were hindering our Mother's care. For example, since I was with Mother 24 hours a day, I knew that she could not be weaned from the ventilator when she first woke up. I explained this fact to them, but they insisted on doing it. I simply said no and the house doctor said I was interfering with doctor's orders and were going to do it anyway. Mother could not breathe and was placed back on the ventilator within five minutes.

While I stayed with Mother, Paul met with the head of nursing, the hospital attorney and the Assistant Medical Director of the Hospital. The head of nursing and hospital attorney presented us with ultimatums. Paul and I could not "interfere" with medical practices, could not help with Mother's care, such as suctioning her (which we did at home) or we would be banned from the hospital. The meeting concluded with these two individuals handing Paul a letter with the above provisions written in letter format. The Assistant Medical Director of the Hospital, Dr. K followed Paul out of the room. He told Paul that he understood that Paul and I genuinely loved and cared for our Mother and that we were not interfering in medical practices. He said we were intellectually above the norm and most of the nurses and doctors did not understand this. They did not often meet families that absorb information quickly and assimilate into the larger medical picture. Dr. K said he would try to help us in anyway possible. The most important assistance he gave us was to identify a highly intelligent, yet caring physician (Dr. R) who agreed to be Mother's permanent hospital doctor (taking her off the rotating physician system). Dr. K was also instrumental in having Nurse Carol assigned to Mother on the weekends she worked.

The understanding of our approach to healthcare by Dr. K and Dr. R made our stay at the hospital less horrendous. The image of the hospital is not completely tarnished due to the caring exhibited by these two physicians.

Involvement is a fourth relational element that Ledingham and Bruning (1998) state brings about a relationship between an organization and its publics. Involvement is defined as an organization understanding its environment and its publics and wanting to be involved its problems and problem-solving processes. Organizational involvement in problem solving for the public brands the organization as a good citizen, a community advocate, and a community-builder. It positions the organizations as loyal to its public.

#### **Pro-Involvement**

When Mother began dialysis we discovered that she needed to eat a lot of animal protein. Paul did some research and found that the chicken nuggets from Chick-Fil-A contained 26 grams of protein. The animal protein helped to distribute fluid throughout her body and not allow it to build up in her tissues. It also helped to increase her albumin level. It was that discovery that led Mother to have breakfast at Chick-Fil-A six days a week. Each morning before dialysis we traveled to Chick-Fil-A. Mother wanted to go to a specific location, Turnersville, NJ, because the people at this one were friendly and attentive to her. Each time the workers, managers and/or owner saw Mother walk in the door they ran to help her into the restaurant. They then ran to make coffee just they way she liked it. She could not eat much so she often ordered the kid's meal, so they rushed to prepare her meal. Each staff member came to talk to her. The owner and his wife sat down and talked with Mother as well as the manager.

One day Mother thought the chicken nuggets were salty. She told the staff this. They tasted the nuggets themselves, opened other boxes and called the district manager and had the entire shipment was pulled! They listened to Mother and saved the rest of their customers from salty chicken nuggets. This was mutual problem solving at its best.

#### **Anti-Involvement**

When Mother's catheter became infected her white count rose to 35. The normal range for a person's white count is 8-11. She was transferred to the ICU. The nurse assigned to Mother was very authoritative. She did not like me to ask questions. I believe it is my right to ask questions. Mother had an order for pain medicine for back pain. The order was PRN--- whenever she needed the pain medicine. It was not a scheduled medicine. At this point Mother was totally de-conditioned so she had to be changed whenever she eliminated or had a bowel movement. She was rolled to a different side every two hours.

One afternoon Mother told us that her back hurt. I asked her if she wanted pain medication. She said yes. I requested the medication. Mother was to receive 12.5 mg and the dosage that came was 25mg. The nurse gave her the appropriate amount and left the remaining amount on her cart. Towards the end of the nurse's shift she told me she was going to give Mother the rest of the pain medication and roll Mother to another side. I responded that Mother did not need the pain medication, but we could certainly roll her. The nurse said she was giving her the pain med. I said no. She argued with me and I said no. She said, "I am her nurse and I will do what I want." I responded, "I am her daughter and you will not give her that medication or I will call my attorney." The nurse told me I was being inhumane. My Mother had never received pain medication prior to being rolled; She stormed out f the room to talk to her supervisor. I called Paul to come to the hospital, which he did.

The next morning Paul went to see Mother and the nurse refused to allow him in her room. He went around this nurse to enter Mother's room and the nurse accused him of physically abusing her, even though there was no physical contact!

The involvement of this nurse was to the detriment of this organization. She imagined the ICU and the hospital as elitist, arrogant and uncaring about the welfare of the patient. This is an image directly opposite of the message communicated on the web site.

Organizational commitment is often considered the most important concept in building and maintaining a positive relationship with internal and external publics (Allen & Meyer, 1996; Mowday, 1998). Commitment creates a psychological link between the various organizational constituencies. The psychological link recognizes the cognitive and affective rewards and/or consequences of behaviors towards the other party. Organizational behavior can evoke loyal or defection on the part of the public.

#### **Pro-Commitment**

After going to Chick-Fil-A for several months Paul filled out a customer comment card indicating that they were kind to their customers. Mother had breakfast and sometimes dinner at the Turnersville's Chick-Fil-A for two years. In July 2011 they noticed Mother had not been in for a week. They looked for the customer comment card Paul completed to find his phone number. The manager called to see if Mother was all right. Upon learning she was hospitalized he personally delivered flowers to the hospital. Two weeks later a beautiful floral arrangement from the owner of the Turnersville's Chick-Fil-A arrived at the hospital. Either the owner or manager called every week to see how Mother was progressing. They offered to bring food to her or anything else she needed. The loyalty this particular Chick-Fil-A offers its customers provokes reciprocal loyalty from its customers.

#### **Anti-Commitment**

I had just returned to my office from one meeting and was on my way to another when my cell phone ringed. It was Paul. My heart sank as I heard his voice because he was crying. He said that he had just been banned from the hospital. I could not believe my ears. Paul was faithful to Mother, especially when I was in Iowa teaching. I asked him how the hospital could do this. He responded that a technician saw him suction Mother and reported him to the head of nursing. It seems Mother was choking, Paul called for a nurse, none came, so he suctioned Mother instead of letting her choke. The hospital administrators would not allow Paul to see Mother at all. We arranged for our private duty nurse to be with Mother at all times until I arrived. Dr. K arranged for Paul to see Mother for one hour a day, but only under guard supervisor. These supervised visits continued for three weeks. After that time period the visiting time increased to three hours, but were timed by the people at the check-in desk. The time increased to five hours then eight. After four months of these timed visits the ban was lifted.

The behavioral consequence of letting a chronically ill patient choke to death because of a nurse not responding to a call for help versus allowing a family member who has been trained by the hospital to suction that patient indicated a lack of commitment on the part of the hospital. This imagines the hospital as not willing to build a positive relationship with their patients as individuals but as patients who are demographics who can only be cared for through the use of healthcare protocols.

### Relationship Management Conclusion

Ledingham and Bruning (1998) state that the five fundamental relational elements of trust, openness, involvement, understanding and commitment establish relationships. The proper imagining of organizations can engender loyalty among key publics. It is important to note that building a positive relationship enhances the reputation and credibility of an organization to its publics. Cultivation of relationships between an organization and its publics occurs when trust, openness, involvement, understanding and commitment is mutually given. When these relational elements are violated or broken the relationship is damaged. It can only be repaired if concentrated and sincere effort is made to cultivate the good will of the party who has been hurt. The task of the organization is to create positivity, which is to perform any task that makes life pleasant for the public (Hon & J. E. Grunig, 1999. p. 14). The organization also needs to assure the public of the legitimacy of its concerns and its entitlement to join in the decision-making process. Over a period of time, however, if a positive relationship and the public concerns have not been acknowledged as legitimate then repair of the relationship may be irreparable.

Yet another rationale is present here. It is one of power. Heath, Motion and Leitch (2010) discuss power in public relations as being allowed and wielded by the public and the organization. It can attribute responsibility of success or blame to a person or entity and it can recreate a human reality. Clegg, Courpasson, and Phillips (2006) talk about power in this way:

"Power concerns the ways that social relations shape capabilities, decisions, change; these social relations can do things and they can block things unfolding. Power is ultimately about the choices that we make, the actions we take, the evils we tolerate, the good we define, the privileges we bestow, the rights we claim, and the wrongs we do. Power means finding the most effective leverage for particular relations" (p.3)

The health care personnel tried to make choices for my Mother that my brother and I felt were unwise. They made choices that, in some cases, denied mother's rights and privileges and ours as her advocates. This placed them in our eyes as abusing their power. Thus as advocates we sought means of gaining power to exercise the better or best choices for Mother's health care.

Clegg et al (2006) go on to say "Power is not necessarily constraining, negative or antagonistic. Power can be creative, empowering, and positive" (p. 2). It is a resource the use of which and the ends to which it is used determine whether it is positive or negative. (Heath et al, 2010.) "The organizational media that form, condense, and distribute social relations shape power and they can shape it either way" (Clegg et al, 2006. p. 2).

This concept of power supports my notion while the health care system may have tried to exert power while Mother was inside their organization and my brother and I, as advocates, fought for her care we have external power in terms of the media, and, definitely, through word-of-mouth. In Heath et al's (2010) terms we have the power to tell the story or relay our family's reality as Mother walked through her health care journey.

With the amount of negative observations I experienced with the health organizations and its personnel, my relationship with healthcare as an organization as a whole has been damaged. Due to my few positive observations, however, and my optimism there may be hope for repair of my relationship with the health institution.

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