

2016

The Complicated Process of Caregiving: The Case of Mr. S (James) and Ms. Q (Sherry)

Nicole Saint-Louis
CUNY Lehman College

[How does access to this work benefit you? Let us know!](#)

Follow this and additional works at: https://academicworks.cuny.edu/le_pubs

 Part of the [Social Work Commons](#)

Recommended Citation

Saint-Louis, N. (2016). The Complicated Process of Caregiving: The Case of Mr. S (James) and Ms. Q (Sherry). *Reflections: Narratives of Professional Helping*, 21 (1), 15-31.

This Article is brought to you for free and open access by the Lehman College at CUNY Academic Works. It has been accepted for inclusion in Publications and Research by an authorized administrator of CUNY Academic Works. For more information, please contact AcademicWorks@cuny.edu.

The Complicated Process of Caregiving: The Case of Mr. S (James) and Ms. Q (Sherry)

Nicole Saint-Louis

Abstract: In the midst of the daily chaos of healthcare and hospital social work, there are tender moments shared with those we serve – moments that make it a privilege to share their journey. Using thick description, the story of two patients is recounted by the social worker that cared for them.

Keywords: caregiving, patient, client, nursing home, oncology, thick description

Each patient's life impacts the professional in a different way. Each patient has a singular experience and the caregiver shares in that journey in some manner. The taxing emotional expense of caring for seriously ill and dying patients in conjunction with other professional, personal, and organizational stressors, is the norm for hospital social workers. Each health care social worker's caregiving experience parallels the emotions and journey of their respective patients merging their distress and stress. However, in the midst of the chaos, we must recognize the humanity in our patients. We must find their strengths in the context of what others might find to be challenges.

Over the years, I realized that in order to survive the rigors of this work I had to have an outlet for my emotions. It is difficult to explain what we do in the care of patients, especially vulnerable patients. I write to not only help in my professional process, but to honor the patients I serve. Social workers become repositories for our patients and their family's stories, but along the way our own caregiving narratives and the silent need to tell their stories emerges. In this paper, I share two case narratives excerpts of a caregiving relationship.

A Note About Theory and Process

Much is written in the social work literature about theoretical pluralism and how social workers draw selectively on various models or methods during practice. A number of theoretical approaches could have been used in thinking about these narratives, including systems theory, the ecological perspective, the strengths perspective, ego psychology, object relations, the working alliance, and others. Also, the social work literature identifies differing understandings between theory and practice. Healy (2005) identified two main schools of thought in

social work—the empirical movement and the reflective tradition. The following narratives are in line with the reflective tradition and can be considered thick descriptions of my clinical experience with two patients, one (Mr. S/James) on an acute inpatient oncology unit and the other (Ms. Q/Sherry) on an acute inpatient physical medicine and rehabilitation unit. Patients admitted to the latter were primarily admitted from an acute care hospital or from the community. The former were most frequently admitted from the emergency department or from the oncology clinic.

Thick description is a type of analysis that helps interpret events and is a process of “sorting out the structures of signification,” while helping the explication of meaning (Geertz, 1973, p.9). Geertz (1973) asserted that it is necessary to study what practitioners do to understand practice. As per Geertz's rationale for the importance of using thick description in understanding detailed case narratives, I incorporate practitioner and patient dialogue.

Writing about my interactions with patients became one method that helped me cope with the rigors of this work. I have done the work of pruning the thick description and redundancies into a narrative so that certain aspects of my interactions with these two individuals are highlighted. The names of the individuals have been changed and certain details have been excluded to maintain confidentiality. The medicalized term *patient* is used rather than *client* as both of these interactions occurred in healthcare settings where *patient* is predominant.

Background

I often have the opportunity to meet patients several times and over several admissions, sometimes the initial meeting is a bit unconventional. On this

occasion, multiple colleagues informed me that a man they described as cantankerous had “social work issues.” Mr. S, a 50-some-year old male, had been admitted through the emergency room late the previous night and arrived on the floor just around 6:00 AM. After I received a consult from my colleague, I checked to see if the patient was in his room. Since Mr. S was not in his room, I read through his electronic medical record and paper chart. As I was reading, another colleague approached to tell me about Mr. S., and at one point, three colleagues were talking to me about Mr. S simultaneously. I recognized this communication as a pleading for me to help provide some relief for them in their caregiving duties as much as a request to help the patient. I noted a combination of frustration and concern as each colleague shared his or her experiences of caring for Mr. S. I knew it was important to meet with Mr. S as soon as possible. However, on each occasion, I would check his room and noticed that he was either off the floor or in the middle of some treatment.

As I read the chart, I noted multiple expressions of exasperation stated in professional medical language, “Patient in need of BID wound dressing. RN attempted to remove bandage and patient refused...” One entry read, “Patient demanded to see the social worker and kicked medical team out of the room...” Each progress note and written entry went on like this. Based on their documentation and verbal reports, he was making their jobs as caregivers extremely difficult. It seemed Mr. S was “a hard stick” and would refuse to be stuck with needles by someone he deemed to be unqualified. However, after much negotiation with the medical personnel, he would finally be convinced of the importance of the procedure and would agree to it. Yet, when the phlebotomist, nurse, or physician would then attempt to take his blood or perform the test, or wound care, Mr. S would protest and become frustrated, often refusing again.

As I was walking down the hall en route to the room of another patient, I noticed a patient was lying on a stretcher in the hallway. The transportation attendant was scurrying around the unit searching for the paper chart for this patient. The unit secretary was helping him in the search. At that moment, a nurse and the unit secretary motioned nonverbally, so as to not alarm him, that Mr. S was the patient lying on

the stretcher waiting for the transport attendant to take him to his next set of tests. I was pleased to finally see Mr. S and I proceeded to introduce myself to him while he was waiting. I planned to tell him that I would be in to see him at a later time in hopes that it would decrease some of his anxiety. Apparently, Mr. S was more than ready to talk to me right at that moment. I reached out to shake his hand and as just as he grabbed my hand, the transport attendant began to push the stretcher. Mr. S continued to hold my hand pulling me with him as the stretcher moved. Mr. S began to speak with a sense of urgency, “I need help with my insurance.” I could hear the distress in his voice.

The patient looked up and said, “Yo, man, can you hold up a minute this is important. I been askin’ to see this lady all day.” I looked at the transporter and noticed that he realized that the patient wanted to talk with me, but he had a schedule to keep and he had to get this patient to catscan (CT). The transporter had already spent a great deal of time running around the floor frantically looking for the chart.

Mr. S, kept talking loudly as if I was unable to hear what he was saying, “I handed in all the papers but they want more...I don’t know...can you talk to my wife cause I need this worked out and my check...” I squeezed his hand and said, “Yes, I want to work with you to get this issue sorted out. I am also happy to speak with your wife. I will come to speak with you later this evening when you return from your test or first thing tomorrow morning. How does that sound?” He nodded in agreement as he continued squeezing my hand. His grip was tightening on my hand, seemingly afraid that I would never return. He then looked at the transporter and said, “I need to talk to this lady now.” It was clear that he was not thrilled about having to go for another scan.

In a soothing tone I stated, “Mr. S, I hear how important this is to you and I agree this is an important issue. Please know I will work with you and your wife. It is also really important that we find out what is going on with your health. This gentleman needs to take you to CT for an important test right now. Would you be willing to put our discussion on hold until we can talk some more?” Mr. S replied, “You promise you will come back?” I promised to return to help address his concerns. Based on the documentation I read in the chart, I believed that Mr. S was eligible for

benefits (both cash assistance and medical assistance). Also, I noted that Mr. S and his wife seemed to be diligently working to get all of his paperwork turned in. He paused, “Really, you sure? You promise you’ll come back and talk to me cause I really want to...” The transporter started giving me *the eye*. If I could see his foot, I am sure he would have been tapping it on the floor, as if to say, “Alright lady, hurry it up, I gotta go.”

I reassured Mr. S and said to him, “I know this is easier said than done, but please try not to worry about this right now.” He squeezed my hand tighter. “What good is worrying going to do for you right now?” He shrugged. “We will work together to get this sorted out either later today or tomorrow morning.”

“You promise you will come back,” he said sheepishly.

I replied, “Of course I will, but now it is important for you to go to this test so we can find out what is going on with your body and your health, alright?”

He nodded in agreement while still squeezing my hand.

“So, will you let this gentleman take you down for your test since we have a plan to talk later?”

“Ok,” he said. I looked at the transporter signifying that they could continue moving. Once Mr. S felt satisfied, he let go of my hand. After I was no longer in tow, Mr. S needed further reassurance so he bellowed from the moving stretcher, “You promise?” as he was wheeled down the hallway.

I replied, “Yes, I promise.”

At this point, I already found him likable and charming. When I reached to shake his hand, he looked up at me from the gurney and there was a mix of vulnerability and kindness in his eyes. I realized he was scared. I theorized that much of his anxiety and his way of coping had to do with his traumatic loss of control from the sudden onset of symptoms and the severity of his diagnosis. He was independent prior to his admission and now he was unable to walk due to a severe pain in his leg. One of the scans showed that a metastatic tumor was

pressing on the bone. The physicians felt that he had less than six months to live. The numerous tests he was undergoing were to determine if he was a candidate for palliative surgery, radiation and chemotherapy. Additionally, he needed to have a central line placed, but up to this point he was refusing.

Although it was after 7:00pm and I was tired, I decided not to go home even though I arrived at 6:30am that morning. I wanted Mr. S to know that I heard his concerns and that he could rely on my word. I felt that if I waited until the morning his anxiety might continually increase and add additional emotional pain. Additionally, this anxiety might spill over into his much needed medical care. Later that evening, I went into Mr. S’s room. It was cold and dark. The curtains were drawn and no lights were on. His head was hidden beneath the covers.

“Mr. S (I always addressed patients with their surname unless they indicated that I call them by their first name). Later, he encouraged me to call him by his first name or nickname. He will be referred to as James (name changed).

“Yeah,” from beneath the covers muttered.

“It’s Nicole, from Social work.”

He peered out of the covers and sat up, “I’ve been waiting to talk to you.”

“Well, here I am,” I commented lightheartedly. Even in this brief banter, I found him charming. He smiled.

He immediately started speaking with a sense of urgency, “Listen I am having trouble with my cash assistance. My wife is going to bring those people all them papers, but could you help? Could you call my wife—[he gave me her name and number]?”

“Sure, I can. Is it ok if I ask you some questions?” He nodded his head. “First, how are you feeling?”

He seemed to relax a bit. “Not so good,” he remarked. This was an opening to be able to talk about how he was coping and to fill in additional details in the psychosocial evaluation.

We proceeded to talk for about forty-five minutes and James candidly opened up about his family history, past intravenous (IV) drug use, and recent incarceration. He was very forthcoming and guarded simultaneously. I could tell he was testing me. He began to talk about his father. Later, I found out it was his “play father” and that he “wouldn’t know his biological father if he saw him the street.” I looked at James’ face as he spoke. He had kind expressive eyes. I could see both the wisdom and the weariness. I knew he was sizing me up as well. He was determining how much he could trust me. He told me some things about himself to see how I would react. He was quite thin and I wondered if he was always thin or if the cancer had eaten away at his frame. I imagined him with more muscle as he described how active he was prior to “coming in [the hospital].” He pointed out self-consciously that his hair was askew and he lamented that he needed a haircut. The nurse entered the room while we were speaking and he gave her a hard time. I mentioned this observation to him. “Aww (gesturing with his hands), She’s always bugging me...” The nurse smiled, and continued on with her mission to give him a low molecular weight heparin injection. Mr. S, of course, continued to give her a hard time. She went about her business and smiled at me. She seemed relieved that I was finally able to speak with James.

“You *are* in the hospital you know (our rapport was growing and I felt strangely comfortable to speak to him openly and honestly).”

I did not have to finish the thought as he replied, “Yeah, I know.”

“I can only imagine how challenging all of this has been. You came into the hospital for chest pain and leg pain and find out that you have cancer. How are you coping with this?”

“It’s hard, but I have to beat this for my kids.”

“How many kids do you have?”

“Two sons and a daughter, but I don’t talk to her much.”

We continued to talk and at the end of the conversation, Mr. S looked at me and said, “Thank

you for comin’ by. Will you stop in and let me know what happens?”

“Of course,” I replied. “I am going to go call your wife right now. We will work together to get this insurance issue resolved.”

“Ok,” he answered.

As I was leaving, I fixed his sheets for him. I noticed he looked exhausted, but he seemed more relaxed. “Do you want the light on or off?”

“You can keep it on,” he said. I saw him reaching for the remote and I handed it to him.

“Good night, Mr. S.”

“Good night,” and as the door began to shut I heard a soft, “Thank you.”

Readmission(s)

One of my colleagues jested with me that “Your guy is here” and admittedly, I looked forward to seeing him. I was curious and concerned that he had been readmitted so quickly. Due to a history of intravenous drug abuse, pain management was often difficult and sometimes he was admitted for that reason, but this time it was more complicated. In rounds, I could see the exasperation on the physicians’ collective faces. The patient never hesitated to give them a hard time, yet they were incredibly concerned about him. He was very sick—sick enough for the doctor to say, “I am not sure he will make it out of here...”

The doctors were having a hard time speaking to him about the seriousness of his medical condition so I asked them to explain it in detail to me. I then offered to accompany the medical team into the patient’s room to help with *the conversation*. They gladly took me up on my offer.

During his hospitalizations, I regularly spoke with James’s wife by phone. James’s wife, Kendra, was very much like him in personality and temperament. I could tell she cared for him deeply and was worried about losing him. All of our initial interactions revolved around concrete issues, namely the insurance application. After we last spoke during James’s previous admission, Kendra went to apply for medical

assistance on his behalf. Up until that point, James had no insurance coverage and no income. He was being cared for by his wife who previously, at least for a little while, he had been estranged from. She was meticulous and followed up on every detail. It was great to work with her.

On this day, she had the number of the Supervisor at the Department of Public Welfare Office and asked me to call because the assigned caseworker would never return her calls. She had advocated as much as she could but needed assistance. I was glad to help. I called the supervisor, Ms. Costa, at the welfare district immediately after hanging up with Kendra. I left a message and awaited her return call. During our conversation, I took the time to explain James's situation (with James's written and verbal permission) and Ms. Costa was more than willing to help. She was actually very concerned that her subordinate had not returned our numerous calls. After a couple more interactions, she had activated his insurance and his cash benefits.

I remember the day I went into James's room to tell him that his benefits were all activated including his cash assistance. I realized that this significant concern about finances was a barrier to working through his feelings about his own mortality. He had been given weeks to live – a couple of months at the most. When I shared the news, the relief showed on his face and he began to tear up. He fought the tears and whispered, "I want to be around for my babies." I wanted that for him also even though I knew the seriousness of his medical condition. I had to balance the need to maintain hope with helping James come to terms with his situation.

Return to Bloodletting

James had stage IV lung cancer that had metastasized to his entire body. The doctors did not feel that chemo or radiation therapy were options any longer as his cancer was already too advanced when he was first diagnosed. Also, they felt that the chemo might further ravage his already fragile body. The medical team consulted orthopedic surgery, regarding a serious pathologic fracture, and radiology to determine if palliative radiation might be advisable. According to the medical team, one of the tumors was incredibly dangerous due to the precarious location near bone and arteries. James

also had an infected wound which was quite significant and was not healing with "a triple cocktail of the strongest antibiotics on the planet." None of the treatments were working and he was still spiking temperatures to 102. I observed the palpable concern on the faces of the physicians, especially one of the residents. The medical team needed to have *the talk* soon, especially to discuss code status. It was deeply troubling for the physicians and nurses to think about performing chest compressions on James's fragile body. The physicians had been attempting to speak with James about the severity of his condition for several days, but they reported that they were unable to make any progress because James yelled at them and would not let them conduct any necessary diagnostic tests.

The team knew I had been working with James and that I had a good rapport. I explained that he is incredibly intelligent and probably knows what is going on but is afraid to hear the details. I shared how difficult it must be for him to lose control. The physicians nodded in agreement and informed me that the James's choices would include: 1.) Surgery, if the surgeons would operate. However, the procedure, if done, would potentially not heal properly due to his compromised immune system and 2.) The antibiotic course could be continued to see how he fared.

On the day we were going to speak with James, I remember that the resident came to speak with me, "He's a hard stick and he won't let me take any blood. I have to go convince him to let me take it out of an extremely painful spot on his wrist. I will come and get you when I'm done..."

The resident was taking quite a while and I felt drawn to the room. I walked in and sure enough James was giving him a hard time. The resident was extremely patient and caring, but he looked relieved when I entered the room.

After the blood was collected, we settled in for a serious chat. I briefed James earlier in the day that we would be having a discussion about his health. At that time, he asked me, "Is it bad? Am I dying?" It was an opportunity to speak privately at length about his feelings. At one moment, he wiped tears from his eyes and looked up at me and said, "So does it just end? Do you just go to sleep and it fades to black?" Words eluded me for a moment so I leaned over the bed and

touched his shoulder. We then talked about his beliefs and we sat together for a while. James let his guard down and for the first time spoke about his fears, pain, and sorrow.

The doctor began to speak about the medical challenges for James. James was calm and asked some very insightful questions. I interjected to help clarify issues or translate medical terms into layman's terms for James throughout the conversation. During this meeting, he decided to make the choice that he did not want to have invasive surgery, even if it meant that he would ultimately lose his life sooner. At this time, James also decided to change his status to do not resuscitate Level A or a DNR-A. This DNR-A meant that all means to save his life would be taken with the exception of intubating him (putting a tube down his throat) and chest compressions ("pounding on his chest"). Although very tough in spirit, his thin body was frail and probably could not handle drastic resuscitation efforts. He shed some tears in our presence and it was a moment that helped open the door further to his confronting his mortality.

I stayed to speak with James long after the doctor left the room and he clutched my hand and said, "I don't want to die. I just wish." and he stopped.

"What do you wish?"

"I just wish that I could have 5 more years with my kids." A lump formed in my throat and my eyes filled with water. I took a deep breath so that I could continue.

"What would you do?"

"I would just..." He could not seem to get the words out so after a brief silence, I added, "You can love them now. Enjoy each other. Cherish these moments that you have together."

He looked at me and stated, "I have done a lot of bad things in my life. Maybe this is..." He stopped and began to cry. I held his hand as he cried and sat in silence with him. I fought my own tears. I realized that he did not see his many strengths. He was an intelligent, caring, humorous, and a loving man. I wished wholeheartedly that he could have more time with his family and that I could ease both his

psychic and physical pain. After a bit of time had passed, I spoke.

"You know what I see?" He looked up at me as he was lying in the bed and I was leaning over him while we talked. He responded with his eyes, urging me to continue, "I see a man who has a great capacity for love and who despite all of his tough talk and antics loves really deeply."

He said, "You see that."

"I do."

We are often interrupted in the hospital and this moment was no exception. It was approaching 5:00pm. At this point, I was emotionally exhausted and I still had documentation to finish. He told me that his wife was on her way into the hospital. He stated that he would love for me to meet her in person. I understood immediately that he wanted me to help with speaking to his family. Every part of me wanted to go home, but I decided to stay at work to meet her. I would return when his wife came into the hospital. I was not sure where I would muster the strength from, but I reasoned that it gave me time to complete my documentation and follow-up on a number of other patient issues. Also, I could see that James was emotionally drained and I was unsure if he would be up to explaining all of the details.

Family Meeting

She came up to me at the Nurse's station and I knew it was Kendra. "Mrs. S.? It's so nice to finally meet you in person."

"Call me Kendra," she exclaimed.

We began to walk toward James's room and she looked at me and said, "I'm scared." She had tears in her eyes. I grabbed her hand and squeezed it and then I hugged her. It was the only thing that could be said at that moment. She fell into the hug and sighed. We went into the room and I basically repeated the conversation that occurred earlier with James, the doctor, and me. As we finished up our conversation it was approaching 6:00 pm and Kendra told me that their sons were coming in to visit. Kendra also asked if I would call her mother and explain everything as I had explained it to her. I would call Kendra's mother

the next day, but I sensed that James and Kendra wanted me to stay and talk to their kids. Even though I was feeling emotionally and physically exhausted from the day, I appreciated their trust in me and I felt honored to be a part of this difficult time in their lives.

Their sons arrived about a half-an-hour later. We situated ourselves around the bed for the family meeting. I said, “[Mr. S] has had a lot happen today. I am here to help explain what is going on with his health and to answer any questions you might have.” I will never forget the look on the eldest son’s face. His body language was indicative of someone sitting on a roller coaster ready to go over the big hill. I began to explain the details of the conversation with the doctor, including Mr. S in the conversation, and making sure he had the opportunity to speak and share his thoughts and feelings as he needed. As we spoke, I watched their faces change – the youngest son turned his head toward his dad and began to pick at his blanket. He then gently rested his forehead on his father’s good leg. His eldest son’s eyes began to show a despair and sadness as if the worst news had come true. I stayed with them for nearly an hour and then left them to spend time together as a family. As the meeting came to a close, I felt an unspoken shift. I could sense they knew the importance of every moment they had together. I said goodbye for the evening and I walked towards the door. Kendra followed me out and at the door and looked up through her tear stained eyes. She whispered, “I love you,” as she reached out to hug me, I hugged her back and I fought the tears from flowing in my own eyes. I thought about responding in kind as I did have a deep and growing affection for this family. I felt so privileged to accompany them on this journey, but I was conflicted because I wanted to maintain professional boundaries. I hoped that they knew that I cared for them through my work with them. At this point, I did not think about my own feelings, rather, I focused on the task at hand, helping this family get to the point where they would be comfortable enough to leave the hospital. The recommended course for the patient was hospice. As James and his family considered transitioning from aggressive medical intervention to comfort care and hopefully, quality of life, in hospice, I wanted to be as supportive as possible.

Ultimately, at the end of this admission, James aka

Mr. S, went home on hospice. I wondered if this would be the last time I saw Mr. S and his family. At this point, I prepared myself that this might be a final “goodbye” and by the time discharge arrived I had given so much of myself emotionally that I was ready for them to leave.

Transfer Request

On a particularly busy day, I was paged overhead at the nurse’s station that there was a call for me on one of the lines. It was Kendra. She shared with me that James had been at home on hospice and he had experienced trouble breathing. Kendra called 911 and she had requested to come to our facility. However, the ambulance, as required by law, took him to the nearest facility. At some point in the conversation, I explained this to Kendra. Kendra asked if I could help facilitate the transfer to our hospital. I knew that we had no open beds and I had little control in prioritizing transfers. I explained to Kendra that the physician at the current hospital needed to arrange for direct admission with an accepting physician at our facility. “[James] really wants to come [to your facility].” I sensed the desperation in her voice. I theorized that she did not want him to die at a hospital she was not as familiar with. Also, I am sure James was adamant and perhaps having a difficult time working with the medical team at the other facility. I acknowledged her emotions. I could hear James’s muffled yell in the background. I pictured him yelling through an oxygen mask. Apparently, in their desperation to transfer, James had even called 911 to take him from his current hospital room to our facility. I admired their tenacity. I could only imagine how the staff at the other hospital was feeling at that moment. I tried to calm Kendra down with soothing tones. I was honest with her that I was not sure what I could do, but that I would make some phone calls and get back to her.

I proceeded to call our facility’s admissions center and to my great relief, we actually had him listed in the queue for admission, but as I suspected there were no beds available. I asked my slightly irritated, probably incredibly busy colleague, “is there any way to know when a bed might become available?” I knew when I spoke with Kendra she would press me for *when* James would be transferred to our facility. She responded that she did not know when a bed would open up. I pressed a bit as I told her that I had a discharge happening shortly. She let me know that

there was a patient already slated for that bed. I knew there was no way to know definitively when a bed would open up so I thanked her for her time and hung up. When I called Kendra back, I let her know that we had James listed as an admission, but that there were not any beds available yet. Kendra asked me what to do. I spoke with both her and James in an effort to calm them. It was clear they had become attached to our facility. The transfer hospital could have provided perfectly good care, but they wanted to be with staff that knew them. James said in a muffled voice, "I just want to be there..." I then heard him yell something at someone in his room. I thought that his feistiness was a positive sign.

Immediately after the call, I felt saddened. I knew in my heart that this would be James's last admission. In two days, a bed opened up and James was admitted to one of our other oncology units in the same building of the hospital. The unit was one floor above mine and was covered by another social worker. However, we all attended the same rounds and I communicated in detail with the medical team and the primary social worker about James's case. The oncology social worker and/or the hospice social worker would be the primary worker on his case, but they both welcomed my continued involvement.

Final Admission

I heard my name in a sing-songy voice. Kendra ran over to give me a hug. "They put us upstairs. I won't be around all of my girls. They are real nice too, but we're just used to here..." James and Kendra had established many relationships with the nursing staff as well. They would have some of the same physicians while others had cycled off service. I watched as the nurses stood around her and talked with her. She seemed relieved to be around staff she was familiar with. In truth, I was happy to see her. However, I was feeling conflicted about seeing James. On the one hand, I wanted to see him very much, but there was something holding me back. I seamlessly compartmentalized my emotions and did not delve further into my reasons for not running right upstairs. I promised Kendra that I would come upstairs to see them, but I purposely did not say that it would be that evening. It was around 6pm and I went into my office and closed the door. I checked email and finished some documentation. I began to

think, *Why didn't I go to see them right away? After all, I had tried to see what I could do to get them transferred here? Why was I relieved that I did not have to visit that night? Why did I feel some relief that they were not admitted to my unit? Had I become too involved?* During that moment, I insisted that I must be tired from an incredibly busy day. I also thought, perhaps I was feeling all of the mounting pressures of oncology work and the many admissions and discharges. I convinced myself that my feelings had nothing to do with the constant death and dying around me and I certainly did not allow myself to think that it had anything to do with James's *last admission*. Instead, I thought about what I would have for dinner and I collected my stuff and went home for the day.

I had rounds on the floor that James was on, but the next day I found myself avoiding his room and on one occasion, I even went in the opposite direction. I began to think to myself, *Why am I doing this?* I felt almost like I was standing outside of myself and looking in, watching from afar. I was talking about him to my colleagues and my fond feelings for him. I knew all about what was going on with his care and that the inpatient hospice team had been consulted. I also knew that many of the staff found it frustrating to work with him. He was tough to work with, but I understood him and I cared for him so *why had I not visited him yet?*

After rounds, I was sitting in my office and my phone rang. It was Kendra. She asked when I was coming up to see them. She put me on the phone with him. At the end of the conversation, they said they wanted and needed to see me. I inquired about the hospice social worker and they insisted that I speak with them. After I hung up, it was eerily quiet in my office and I put my head in my hands. My mind was blank. I was numb. I then thought to myself, *it's already 4:30pm, I will just go see them tomorrow*. For a moment, I allowed myself to think, *what am I feeling?* Frustrated with myself and unable to pick an emotion or more, I gave myself permission not to go visit that evening. Even though, I made this deal with myself, I was still thinking about it at 5:00pm. I finally decided that I would stop in after rounds the next morning.

As it turned out, I actually popped in their room before I went to rounds. As I knocked on the open door to the hospital room, I noticed James was sitting up in bed

and Kendra was sitting on the side of the bed leaning on him. I could see how much she loved him. I smiled and I said, "Hey you."

He looked at me. He had the mask on his face and it was incredibly loud. His eyes smiled. I touched his hand. "We been waitin' for you," he said. Kendra came over to hug me. They were so happy to see me and I them. *Why did I wait to come up here? I felt a tinge of guilt.* "Sit down, here you go." Pointing to a chair. I accepted the chair and she began to speak quickly. They shared that they wanted to make their marriage official and were asking if I could help. I let them know that I would look into it and get some information for them, but I silently noted that James did not look well and was struggling to breath. He stated that he was feeling "sluggish" and asked if I could return later. I said that I would come back that afternoon with updates.

I returned to his room around 3:00 pm and he was grumping at the nurse.

"Hi James, how are you? Are you giving these ladies a hard time up here?"

"No I'm just sayin' this mask ain't right. It's too loud."

I turned to the nurse and I said, "What do you think about an AquinOx™?" She thought it was an excellent idea, but the doctor had to put in an order. The issue was that at his current saturation levels most people would be intubated, but he had decided not to return to the intensive care unit. Many of the staff were avoiding his room because he gave them a hard time. I looked at him and I knew right away that he was terrified. I watched helplessly as his chest struggled to grasp each molecule of air. I called the physician and spoke to them about the AquinOx™ which would be much quieter and would force the oxygen into his nose so he wouldn't have to wear the loud mask which prevented him from eating (for pleasure) and talking. After speaking with the physician, the nurse left the room and went to call respiratory. In the meantime, I helped James try to get comfortable.

"Move my foot."

"Please," I retorted.

"Please," he responded with a grin.

These were my last moments with him...

"We then began to communicate nonverbally. I rolled up a pillow and put it under his head and we moved in this silent way both of us trying to alleviate his apparent discomfort and air hunger. In the midst of this awkward dance, he made us both chuckle when he stated with a delivery that was quintessentially his, 'I'm going for the 'L' shape.' Ironically, I immediately understood what he meant because it helped maximize the flow of oxygen to his labored lungs.

After we managed to make him less uncomfortable, I sat in the chair next to the bed. I knew he was tired, not just physically tired, but emotionally. He was ready to go soon.

'James, it's ok if you want to go to sleep.'
He replied, 'you ain't gonna leave me is you?'
'No, I'm right here. I will sit with you for a while.'

I thought I would try to stay until Kendra came back so that he would not be alone. I was hoping she would not be too late as I thought about all that I had to do before days end, but I chose not to worry, and to sit and absorb this moment. I sat still somewhere between tears and stoicism. I sat in the nondescript concave blue chair next to a sleeping James as a swirl of emotions rushed over my person. I thought about my first interaction with James who was admitted through the emergency room for an orthopedic issue, only to find that it was caused by metastasized tumor from his stage IV lung cancer. James pulled me out of my thoughts with a whisper, 'I feel like the devil is on top of me...' My heart sank and I felt a chill in my spine.

'What makes you feel like that?'

'I've done a lot of bad stuff in my life.' I chose to comfort him and to engage in a discussion about his spiritual beliefs. Later I would ask the Chaplin to stop in and see him as well. He stated that he talked to God all of the time and that his ultimate comfort came through his redemptive relationship with his Creator. Silence fell upon us once again with only the sound of the oxygen flowing through

his mask.

‘Are you scared?’

‘Sometimes.’

I just rubbed his hand and my heart ached inside my chest. We sat like this for several moments and I said; ‘we knew it was going to happen, we just didn’t know it would be this soon.’

He shook his head as a tear trickled down his cheek, ‘I wish I had more time.’ I fought back the tears welling in my eyes.” (Saint-Louis, 2014, p.35)

As we sat waiting for his beloved to come, respiratory came with the AquinOx™ apparatus (nasal cannula). He, in true James fashion, gave them a hard time, looking at me with his mischievous smile. I watched at his side as they put the AquinOx™ on him. He was panicking because he could not get air, but he calmed down and the respiratory therapists left as their job was complete. I resumed my spot in the chair and James drifted off to sleep. I soaked in the moment and felt genuine love towards this man. He seemed more peaceful and less agitated.

Soon after the respiratory team left, his wife called and stated that she was running late and would not be in until after 7:00pm. I knew it was time to say goodbye. I went over to him and kissed his forehead, “I love you he stated...nobody has been like you.” “I love you too...” my voice trailed off and I squeezed his hand. As I exited the room I had tears in my eyes.

They had been together for most of their lives and they complimented one another. They were a feisty couple that often showed their love through sharp barbs and heated debate, but their relationship lasted the test of time. My little slice of time with James consisted of 28 hospital days and 3 months in total. The narrative about James was not written in one sitting. It was written in pieces over time. The quoted section above was written in the context of one session of Narrative Oncology rounds (Saint-Louis, 2014).

Reflections

The formerly “angry and combative” Mr. S could have easily continued to be categorized negatively as

angry, “uncooperative,” and “noncompliant.” It was important to take the time to observe and work with him and his pre-existing strengths to help him cope with the reality of his situation. James was incredibly resilient and a survivor in every sense of the word. He had endured unspeakable abuse, racism, and yet found a way to make a living and care for his family. He overcame so many obstacles and managed to keep his family together. His sons were educated and working in great jobs and his wife adored him. He showed his loving, sensitive side to a select few. He allowed himself to be vulnerable in my presence and I cherished this privileged trust he had in me.

According to the NCCN (2015), approximately one third of cancer patients experience significant distress and only five percent obtain psychological help. Although, the distress does not impact the cancer directly, it does impact how patients cope with their cancer diagnosis and their subsequent ability to follow the recommended course of treatment. Social workers on the front lines have the unique privilege to provide emotional support to patients, especially in an inpatient setting. However, we have to be aware of our own emotions while working with our patients. There were times when I was working with James that I did not acknowledge or deal with my own feelings. As James’s social worker, I also experienced distress throughout my interactions with him. I felt and internalized his stress, distress and other emotions, but I did not allow myself to cry or even to have my own feelings in his presence. I was *the professional caregiver* and I never wanted him or any other patient to feel the need to take care of me. As I reflect on the above narrative, it is much clearer that there were moments where I was depleted or that the reality of James’s shortened life had become painful for me. I question whether I should have expressed my care for him. Ultimately, in our final moments together, I made the decision to express my “love” for him. Much can be written about boundaries, transference and countertransference and I could argue the benefits of not sharing in this moment. I chose to respond in kind because I wanted him to know that working with him had touched my heart. I wanted him to die knowing that I cared. I do not even know if he heard me. Ultimately, I will cherish the time I had with him and his family. Writing about James allowed me to finally shed the tears I had stifled, helped me to see places where I might have helped in a different way, and ultimately, it helped me to cope.

Ms. Q (Sherry): Psychosocial Evaluation and Ongoing Work

Initial Note: Psychosocial Evaluation: HT: 5'1 WT: 375lbs Contact Person(s): Daughter 21 #.###.####; sister 21#.###.###, sister 21#.###.#### PCP: Dr. I. M. Caring 21#.###.#### Pt. is a 65-year-old female, single, with one adult daughter. Pt. lives alone in an apartment with no steps to enter and is wheelchair accessible. Pt. was well connected with community services and was known to the City Corporation on Aging and had a home health aide provided through B Home Nursing Agency for several hours a day. Pt. has good social supports. Pt.'s family, nieces and daughter assist in getting patient necessities, groceries, etc. Pt. states that she does not use tobacco, ETOH or illicit drugs. Pt. became tearful and shared some very difficult experiences with SW. Pt. discussed her desires to "go out and see the world and how it has changed...new buildings that went up..." Pt. states that other than medical issues, i.e., inpatient hospital admissions that patient has not been "out [of her home]." Pt. stated that she has suffered from "bad nerves" and depression as well as "worrying about sickness." Pt. described how her dream is to "stand up and jump for joy." Pt. described that she desires to "get glasses," and get her "teeth fixed." Pt. reported appreciation for being able to talk about her feelings. SW will continue to work with patient, family and insurer to set up appropriate services and order needed equipment or restart services that were in place prior to admission to rehab. Please call with questions. NS-L 21#.###.####

Admissions and Introductions

Ms. Q (Sherry) was an inpatient on the rehabilitation unit at the hospital. Her story serves as an example that daily interactions with patients can be used to uncover patients's viewpoints, feelings, fears, and preferences for their medical care.

I first heard about Ms. Q through the admissions coordinator who stated that the patient would be coming to the rehabilitation unit and that she was "high profile." She was high profile because her case had been featured on a special program on the local city news channel. I also received an informal briefing from the attending physician. The attending

physician, a renowned lymphedema specialist, admitted Ms. Q to the unit to see if we could help. She knew that Ms. Q had a complicated psychosocial history and she was eager to have me evaluate and work with the patient. As the social work case manager, I was responsible for the entire coordination of each patient on my service. This coordination included utilization review with the insurance company. The admissions coordinator obtained prior authorization for Ms. Q's initial week on the unit. A follow-up review with the insurer was due a couple of days after Ms. Q was admitted. It was clear that the patient would require a great deal of equipment and lymphedema supplies upon discharge. Some of the supplies needed to be ordered in anticipation of the patient's admission as these were specialty items that would not necessarily be available in the hospital or acute rehabilitation unit. In an effort to get as much detail as possible about Ms. Q, I researched the local News website that had links to the broadcast that featured Ms. Q's story.

Upon admission, I attempted to meet Ms. Q on at least two occasions prior to our first meeting, but both times her room was full of therapists, nurses and the attending physician. Ms. Q's story began long before the television cameras were on and long before our hospital's inpatient rehabilitation medicine unit agreed to accept her for care. According to the physician, "Sherry came into this world with a compromised lymphatic system, plus it was further damaged by the surgeries she had."

Sherry later referred to the surgeon as "the butcher." "He didn't even say he was sorry. He didn't even have the decency to come and talk to me himself. He just cut me open and left me there with a hole in my leg and an infection and had his resident tell me I could go home."

The first thing I noticed about Sherry, when I finally got to talk to her, was her expressive eyes. They showed the depths of her pain, her yearning to be loved and accepted, as well as her considerable skepticism of any new "caregiver in the room." However, in our first couple of meetings, she chose to close her eyes for a portion of the conversation. Initially, I thought perhaps it was the pain medication, but later I realized Sherry had a lot of experience with healthcare providers. She also had good reason not trust her caregivers. Her trust had to be earned and she

was sizing me up to see how I would handle talking to her. Her body language intimated that she was not truly interested in what I had to say.

“Hi Ms. Q, my name is Nicole and I am the social work case manager that will be working with you while you are here. Do you feel up to talking right now?” She peeked at me through one eye and then closed it. I stated that I might ask some questions that overlap her previous conversations, but that I would appreciate her patience with the process. She kindly told me that it was no trouble. I began the typical psychosocial evaluation conversation. I noted her body language and I could almost hear her silent voice and her closed eyes saying, *Yeah, yeah, lady I heard it all before. People promise the world and don't deliver. How are you going to help me?* I knew I had to be patient with Ms. Q and that this would be the first in many interactions because it was about developing rapport and hopefully, a relationship, so that I could find out what she needed and help her return home safely. Ms. Q said she could not recall a lot of the specifics like phone numbers during our conversation. I told her I would see if I could find the numbers and then I would run them by her to see if they were correct. I believe this was one of my first tests.

I knew Ms. Q had agreed to be admitted to our hospital and that in spite of her skepticism, she had some hope that we could help her.

The conversation moved slowly with short polite answers to my questions. After the conversation went on like this for a while, I stopped and looked at Ms. Q and asked her, “What would you want to come out of this [admission]?” Her eyes popped open and lit up and she looked at me. So much happened in that quick glance. She was completely awake and engaged. She replied clearly and frankly, “I want to jump up and shout for joy!” “Can you tell me more about what you mean?” She took a deep breath and began to tell me what happened to her. “It's been really hard. Really, really, hard. I hid from people and didn't want them to see me.”

Ms. Q discussed that she was embarrassed about going out in public. “I used to sit on a commode all day” because she had no other chair that could comfortably accommodate her. Ms. Q shared with me at one point she was admitted to another hospital

and “the doctor operated on [her].” She stated that the surgeon performed liposuction. “He thought it was all fat and not fluid,” she stated. “He cut me open and left me like that to die. He is just one of the many...”

“How did you ever feel comfortable returning to a doctor after that?”

“Well, I didn't for a long time. It was about 6-7 years. Even when I knew I should go and my family wanted me to, I wouldn't go.” As she spoke, I thought to myself, *I do not blame her.*

Ms. Q described vividly her feelings of being trapped. Essentially, her body, a prison of flesh and fluid, held her hostage. If you were to take off the nearly 250 pounds of fluid, Ms. Q was actually a tiny woman. I now knew what she meant about jumping up and shouting for joy. I pictured her leaping out of her bed and running down the hall, dancing and shouting. At that time, she was unable even to walk. The hope was that as the lymphedema was reduced and she got stronger through physical and occupational therapies, she would begin to walk household distances and then perhaps the length of a city block. Ms. Q described the days leading up to her admission to the rehab unit of the hospital. She reiterated that she sat on a plastic adjustable commode all day. She told me that she wanted to get a lazy boy chair or recliner she could both sit and sleep in. From that moment on, it would be my mission to get her that specialty chair.

“They used to call me the elephant lady. *They* did, a nurse did, a nurse. When they put me in the Nursing Home. I saw a lot of bad things in that home. I saw a lady scream all night that she was in pain and she was bleeding all night. They brushed her off like she was crazy.”

What happened to her?

“She died.”

“Ms. Q that must have been so scary.”

The more she talked the less guarded she became. I came to admire Ms. Q very much for her courage, strength, and resilience. Most people, including me, feel self-conscious for things that are a lot less serious. Sherry, (she now insisted that I call her by her first name) stayed at home for thirty years. She was

transported to and from her home only when it was a medical emergency. She never shopped for herself. She stated that she did not see the new apartment building being built down the street or get to feel the wind in her hair while riding in an open car with the window down. She could not remember the last time she bought shoes.

I touched her arm as tears trickled down her soft, and radiant cheeks. She did not know it, but she had a light that emanated from her even when she was hurting which I suspected was most of the time. I wished I could remove her considerable pain and suffering. I wanted her to know how special she was. I touched her arm as tears flowed down her face. I hoped this touch could compensate for the inadequacies of my words at this time. She leaned into my touch. Other than the contact that comes with medical care or that of a wound care regimen, I suspected that normal human contact was frequently absent for Sherry. Over the years, I observed that when people are sick, people avoid touching them. Family and friends sometimes had to be encouraged to touch their loved ones.

At an appropriate moment during our conversation, I asked Sherry what she thought of her ReidSleeves®, the big boot/compression garments, and the lymphedema wraps that were keeping her legs from filling up with fluid again. She replied, “It’s a miracle.”

“Is it painful?”

“Oh the pain, you just don’t know.” I knew she was talking about more than the wraps on her legs.

“You are so strong Sherry. You are an amazing woman...” I wanted her to know that I saw her, the whole person – the beautiful, smart, courageous woman. I wanted her to know that she was more than just her lymphatic extremities.

I let Sherry know that I would advocate for her to the best of my ability, but I made sure to never promise anything I could not deliver. I told her what homecare and medical equipment resources I thought could continue and I discussed the medical equipment items that might be more difficult to obtain. It was clear without having to ask that she would never return to a nursing home facility even if

it was vetted and visited by her family. She needed a great deal of specialized wound care supplies, around the clock care, a specialized wound care mattress, wound vacs, a specialized wheelchair, and of course, the recliner/lazy boy-like chair. I asked her what she thought of this initial plan for resources and I followed-up with her at every point in the process. I made sure she participated in every decision and I kept her updated frequently. I wanted to continue to build her trust, to empower her and to decrease any anxiety about what was happening.

Preparing for Discharge

We had been working with Sherry for several weeks and she was due to be discharged the next week. I was going to be away at a conference when Sherry was due to be discharged. In anticipation, I made all of the arrangements for discharge and the coordination of care before I left. Sherry did not have computer access at home so I created a binder of resources for her and her family.

We were able to piece together 24-hour specialized care. In order to get the medical equipment, I wrote a letter of medical necessity that both the attending physician and I signed. I had most of her wound care supplies delivered to the hospital so that they would be transported home with her. I wanted the nurses to make sure they were all the correct items she needed and to practice the night before she left with her own supplies. The nursing staff diligently trained Sherry and her family on the details of wound care. All members of the interdisciplinary medical team worked to make sure that Sherry and her family were trained and worked to ensure the safest possible return to her home. In the binder, I included all of her contacts at the various nursing and physical therapy agencies, the medical equipment companies, the hospital and the City Corporation on Aging. I included some inspirational quotes and I put a schedule template in the binder that I asked the team to fill in for Sherry. This would help her and her various healthcare providers to keep track of her extensive wound care regimen.

As a result of the television broadcast, a fund was started to help Sherry with her considerable expenses, but there were limitations on its use. I spoke with the fund manager about paying for certain specialty items and made sure that all of the necessary paperwork was

in order. I arranged Sherry's next three follow-up medical appointments and the requisite transportation. I discussed the detailed discharge and follow-up care plan with all of the members of the medical team during our detailed weekly interdisciplinary rounds.

I returned to the hospital after my time away and within an hour and a half patients were filling the physical therapy gym. I noticed Sherry was there. She had not been discharged as planned that past weekend. She was lying on one of the elevating mats in the gym and she gently lifted herself up and smiled a cheerless smile at me. She did not look like the same Sherry that I left before the conference. I went over to Sherry and she whispered, "They took me to surgery. They closed my wounds. I am in so much pain." She seemed noticeably uncomfortable being on display in the middle of the physical therapy gym. I went over and sat next to her with my legs crossed. Her previously braided grey hair was pulled out of its proper place and she reached out to hug me. As she spoke, I could hear the despair in her voice.

The nurses arrived to change Sherry's bandages and the smell of pseudomonas was immediately identifiable. I knew the smell upset Sherry. Sherry, for as encumbered as she was by the lymphedema and her body, she was well taken care of and took pride in "being clean and smelling nice." Her family told me a story of how Sherry would take her sheets and clothes and clean them in the bathroom sink before she would allow them to take the sheets to be washed. I remember her daughter saying, "She would be in the bathroom forever and when she came out, those sheets were so clean and dry they looked like they were already washed." Before she came into the hospital and during her hospitalization, Sherry continued to take pride in her personal hygiene. It was often difficult for lymphedema patients to attend to all of their activities of daily living due to reduced mobility. However, Sherry wore pretty housecoats with flowers and several members of the team reported that they had never worked with a lymphedema patient that was as diligent in their personal care. I was happy that the nurses thought to put up a privacy screen. Sherry was in so much pain, tears streamed from her eyes. I hugged her and told her I would let the nurses "do their thing" and I would see

her later. As I walked away, my heart sank. I was right to be worried while I was away. The wrapping of her stage III lymphedema, although effective and healing in its own way caused her tender flesh to be stripped away from her leg and in some places was so deep that it had become infected. Two debridement procedures were necessary a couple days before she went to surgery.

The next day, Sherry was in her wheelchair and rolled by my office so I came out to see her. "Sher, how are you today?"

"Not so good. They buried my brother today..." My heart ached for her.

"Oh, Sher, I am so sorry to hear that. It's just one thing after another..."

We spoke about her brother and their close relationship. Prior to this series of unfortunate events, she was improving physically and psychologically. The whole team noticed that her functional status declined since the surgery and now with the death of her brother, she had become increasingly depressed. When Sherry told me that she was in the middle of therapy, I promised to catch up with her later. "Hi Sherry," Now much later in the evening. Sherry was back in her hospital bed, but she turned and lifted her head and showed some light behind her deep brown eyes. She reached for my hand.

We started to talk and she said, "Do you know what's wrong with me?" I knew what she was asking because she had asked another member of the team earlier in the day. As my colleague and I were discussing Sherry's concerns, we realized that it was a visit from Infectious Disease that led her to believe that she had something really wrong with her. "They came in and they examined me and they left."

"Sherry, I know it sounds just awful, but the doctors consult Infectious Disease (ID) when they are worried if you might have an infection. They are worried about the wounds that you have and they want to make sure they have you on antibiotics and the proper antibiotics for that infection."

She looked at me as I began with skepticism, but then her eyes changed and I saw a glimpse of trust. However, she still seemed so sad. "Sherry forgive me

for not staying down where you can see me, but my knees were starting to hurt.” There were no chairs in the room and I hated standing over patients when I talked to them. Once my knees were stretched I got back down at eye level.

“Sherry, were you told why those doctors came into see you?”

“No they just came in, did their thing and left. You know I am just sick of people talking about me like I am not here.”

I heard her concern. I also knew that no one meant there to be any harm to Sherry. The medical team most likely consulted the ID team, but before they had the chance to speak with her about it, ID met with the patient. I spoke with the medical team about this and the physicians later came in to speak with her.

In the moment of our conversation I responded, “I am sorry, Sherry. You are right to feel the way you do and you have every right to be upset. You just want to know what is going on.”

She looked at me and nodded her head. I chose not to make excuses and rather to apologize on behalf of the entire medical team, as she needed her emotions to be acknowledged. I then began to answer her question:

“I think I would be so scared if someone came in and said they were from Infectious Disease and I did not know why they were here. As far as I know Sherry, there is nothing *wrong* with you. You have some health issues that we already know about and are actively treating and managing.” I went through each of her diagnoses with her. “You have CHF, but that’s under control... You have diabetes, which is being managed... As you know, it is important to keep a close eye on your wounds because of the diabetes. Plus, the lymphedema or the swelling in your legs continues to need wrapping. Now you have these boots [pointing to the ReidSleeves®] and the wound vacs are for helping the wounds that you have on your legs to heal faster. Does that sound about right?”

It was a good opportunity for us to review her healthcare issues. “Sherry, you are one of the

strongest people I know. That’s what I see when I look at you – strength and determination.” I rubbed her shoulder and touched her forehead, moving a tuft of hair from her face. She leaned into my hands and took a deep breath. We sat like this for a moment. “Is your family coming in tonight?”

“No they were here for a long time yesterday.” I asked how her legs were feeling.

“It hurts a lot.”

“Do you want me to get the nurse to get some more pain medication?”

She replied, that she did not want to have any more pain medicine, “because one time it almost stopped my heart.” I thought about how much she had to contend with on a daily basis. It must have been exhausting, yet she persevered. I noticed a change and I was worried about her. She seemed to be slipping into a depression, which I shared with the medical team. As we continued to talk a young woman dressed in a white coat, potentially a physician, yelled to me from the doorway. “Why is she on contact precautions? Is it necessary to wear the gowns?” I felt a bit annoyed with the consulting physician, even if she did not mean any harm, because Sherry was quite fragile at this moment and the physician did not address Sherry directly and inquired about her as though she were not there. It was helpful to witness as it gave me some insight into how Sherry might feel with all of the consultative services in and out of her room.

I looked at Sherry (she looked so hurt) and before responding to the physician’s question, I asked her, “Do you know why you are on isolation precautions?” She nodded that she did not know why staff wore gowns in her room.

I looked at the physician and I politely replied, “I think you should speak with the nurse.”

It gave me a chance to ask Sherry again if she knew why everyone wore gowns and gloves in her room. I explained that the gowns are probably used for the same reason that she needs antibiotics and I answered any questions she had about isolation precautions. I urged her to speak with the nurses and the doctors about her concerns and questions, and that I would speak with them on her behalf as well. I reminded her

that it was completely appropriate and within her rights as a patient to know what was going on with her medical care – why she needed certain meds? Why are the doctors here?

As we were talking, the same doctor came in and said, “Hi Sherry. I am from Psychiatry.” Sherry looked at me with fear and concern.

I wondered if the doctors had the chance to tell her they had consulted psychiatry. I told her that I would be back to touch base with her before I left for the day. In the meantime, I spoke with the nurse and the physicians about the consultations. Later when I returned, we talked about why psychiatry came to see her and I discussed that the staff was concerned about her increased sadness from everything that is going on and the death of her brother and that they were thinking that she may need some different medicine.

“I just wish they would talk to me...”

At that moment, the nurse and attending physician walked in and we all discussed these issues with her. She seemed satisfied with this discussion.

As I was leaving her room, she thanked me and as I was almost out the door, she whispered, “I love you.”

Post-Discharge Reflections

Sherry lived for several more years. We maintained contact as I continued to arrange her transportation to and from her appointments for several months until we could transition to the outpatient team and she felt comfortable. Every once in a while, Sherry would call and leave a message for me. Once she left me a message, “I just wanted to hear your voice.” On one particular day, I received a call from the emergency department (ED). The physician told me that Sherry and her daughter were in the ED and were asking to see me. I was both worried and excited as I made my way to that part of the hospital. Once I arrived; I could see that Sherry was clearly in pain, uncomfortable and struggling on the small emergency room bed. She reached out for a hug and thanked me for coming. She wanted my help in explaining what was going on with her care. I knew she was scared. I stayed while the medical team explained that she would be admitted to a medical

floor. I spoke with the medical team on Sherry’s behalf and translated issues to Sherry. The ED social worker and I worked together to help Sherry adjust and before too long she was smiling. Sherry had several admissions to the hospital over the years and each time she came in she would call me.

Conclusion

These excerpts can be considered thick descriptions of my experiences as a social worker on two different healthcare service settings. In part, the very act of writing helped me to reflect back on these experiences and think holistically about these patients. It also helped me to process my own emotions and it allowed me to see the humanity of James and Sherry. Writing about these two individuals also provided further insights into the vulnerability patients feel when they are sick and ultimately it allowed me to appreciate their trust in me. Additionally, I am able look at the content of the experiences of working with folks that are ill, vulnerable and skeptical of the very system that I represented. The ability to collaborate with these clients, while meeting them where they were was paramount to our ability to move forward.

In the health care setting, especially in a hospital or acute rehabilitation unit, the ultimate goal of the insurer and the institution is discharge. Social workers play a key role in the discharge process and in order to achieve a “safe” and acceptable transition to home or another facility, social workers provide emotional support to deal with the complicated stress and distress of our clients. While working with and focusing on client distress is critical, social workers might be inclined to ignore their own feelings and the overall impact of working with complex and vulnerable patients.

Beyond case narratives, research, especially rigorous qualitative research, is needed to further elucidate the complex relationships social workers have with their clients in healthcare settings. In particular, attention should be paid to stress, including secondary traumatic stress, distress, compassion fatigue, and burnout. These two narratives exemplify that the process of professional caregiving for those that are ill often involves an intense relationship that does not abide by the normal conventions of hours or time. These caregiving relationships frequently extend beyond the bounds of admission, discharge and the traditional

therapeutic relationship, and leave both patient and clinician forever changed. With that knowledge, we, the professional health caregivers must also find a way to take care of ourselves.

References

Geertz, C. (1973). *The interpretation of culture: Selected essays by Clifford Geertz*. New York: Basic Books.

National Comprehensive Cancer Network. (2008). NCCN Clinical practice guidelines in Oncology™:

Distress Management: The Official Journal of the National Comprehensive Cancer Network, 1, 1-45.

Saint-Louis, N. (2014). Writing to cope: Meaning-making for professionals caring for the cancer patient. *Reflections, 20, 26-39.*

About the Author: Nicole Saint-Louis, DSW, LCSW, Assistant Professor & Program Coordinator, Human Services, CUNY-Guttman Community College (nicole.saint-louis@guttman.cuny.edu.)