

That's What a Social Worker Does

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Abstract: This article describes the frustrations of navigating the healthcare system as the daughter of an ill parent, rather than through her role as a professional social worker. Having tried to gain a sense of safety in what seemed to be a most unsafe situation, particular attention is focused on interactions with social workers and whether my personal experience in that role, in a very different venue, was a help or a hindrance.

Keywords: Client centered

My dad was finally home, safely asleep in his bed after a 21-day hospitalization. As I sat there beside him in the darkening room, I thought back to the story a doctor told at a conference I had recently attended, and how it had so directed my focus to the aspect of safety.

In the story, the physician's teenage patient was in labor, and her very large and anxious family was rather disruptive with their constant questions, challenges and concerns about the pain she was having. After explaining the several options for anesthesia, the dad adamantly rejected the idea of an epidural because he feared putting a needle in her back would cause paralysis.

After careful discussion and explanation, the patient herself, elected the epidural, which was quickly and easily administered with the expected result of her being in much greater comfort. When the doctor stopped by later, only three of the original 10 family members remained. She asked the dad where everyone had gone, and he explained that they all felt they could leave because the girl was safe and didn't need their protection any longer.

This story resonated strongly with me. During his time in the hospital, frightened enough for his precarious health, my family and I rarely felt safe. We were constantly worried that we had to be physically present to protect my dad from a system that seemingly would not.

My dad is a white, upper middle class male with one of the best and most expensive health insurance plans available to anyone in this country. He is certainly not a person who has to worry about getting optimal health care or facing the barriers of disparities or discrimination. Nevertheless, my dad and our family could not escape the sense that the health care system was fraught with issues that caused great concern for his safety at a time he was

the most vulnerable.

I have been a social worker for 17 years and admittedly hold my discipline to a much higher standard than I do the rest of the health care system. No other health care provider's job description is mandated in quite the same way as by the core values of social work: service, social justice, dignity and worth of the person, importance of human relationships, integrity and competence (NASW, 2014). And yet, while I could certainly speak to the ways the MDs and other health care providers disappointed me and my family on a daily basis, it is for this particular reason I was so dismayed when I encountered the uncaring, unhelpful responses from social workers in my attempts to negotiate with the health care system for my dad.

Social workers should rise above the system and provide empathy, caring and support; it is our job to provide health care in a different way. We pursue change for vulnerable populations and do not stand by as the status quo creates barriers. Social workers emphasize the importance of relationships and a therapeutic alliance that above all shows clients that we care about them and empathize with their situation, even if we can't fix their problem. Social workers know the rules of the health care system and advocate for change; we ask for things that other health care providers wouldn't expect anyone to ask for because we know that challenging these systems is what will put the wheels in motion for positive change in the future.

However, I must also recognize that the venue I have worked in all these years may be different from that of a hospital social worker. My experience is in small, grassroots organizations that emphasize clients' rights and social justice, aligning perfectly with the mission of social work. Being a social worker in a large hospital system likely means that you are facing a bureaucratic system that has explicit rules that state the

patients' needs come first—while maintaining implicit rules that we must be able to bill for services, meet the needs of an overwhelming caseload, and follow an unwritten hierarchy that the doctors' opinion is the right opinion. A hospital staff follows the medical model wherein diagnosis reigns: a health care provider imposes their opinion on the patient, and tells them what is wrong with them and what must be done to fix it.

Social workers believe in assessment in which both the client and the social worker work as a team to formulate what the problem is and how to work on goals they set together. This is rather incongruent with the hospital's top-down hierarchal decision-making process. For me to expect hospital social workers to be in constant rebuttal of their co-workers and the system in which they work was likely unfair. As I think back to the situation, I can see that my concern for how my dad was being treated was not only about my mistrust of the system in general, but was reflective of my feelings about how health care should be, rather than trying to work within the realities of how it is.

In the ICU

Even though my family had been sitting bedside with my dad in the ICU—sometimes all night and all day—we were not able to talk to a doctor for more than a minute at a time, and certainly not all of his doctors altogether.

One big concern was his evident cognitive decline. He was often so confused that he didn't know me from anyone else there, eyes wild with panic of the unknown. On one of his better days, we were watching TV together. My dad knows all sports better than anyone else I have ever met, and tennis was one of our favorites to watch together because I had played in high school. He didn't look or sound any different to me but he said, "Look at Venus, she's doing better than the rest of them and she doesn't even have a racket in her hand." I started to question him more closely, and to an observer who didn't know my dad, it really just sounded like he didn't know much about tennis. Anyone who did know him, however, would know that something was seriously wrong. I tried to no avail to help his physicians understand that he had become confused, but because he knew where he was and what the

president's name was, they did not address my concerns until his confusion was much worse.

Most of my dad's 21-day stay in the hospital was in the ICU where he was hooked up to many machines, unable to move about on his own. He was growing increasingly frustrated and uncomfortable, and was becoming more and more debilitated. The ICU's devices breathed for him and monitored his condition closely, but we would never get closer to an actual diagnosis or treatment for him. He came out of each ICU episode weaker and further from his 65-year-old baseline.

The first time I actively sought assistance really stemmed from my faith of the social worker's advocacy for the whole person. I felt the physicians were not talking to my dad—or to us—about what was wrong with him and what they were trying to do to help him. He had been in the hospital for 10 days and we didn't have a diagnosis nor an intervention yet. Often their answers were that "the other team is working on that." To them, it seemed, he was a kidney, a lung, a heart. Family members of patients in the ICU need information about the patient's condition that is clear and understandable. The way they receive the information is equally important. The environment itself is so overwhelming and it needs to be discussed in language that allows for a mutually respectful relationship between the family and the healthcare team (Auerbach, Kiesler, Wartella, Rausch, Ward & Ivatury, 2005). It has been documented that patients feel most cared for and secure when doctors avail themselves for consultation and demonstrate ease with family members (Bendapudi et al., 2006). A multidisciplinary team approach is recommended; it is easier and more effective to speak with a cohesive team rather than numerous individual specialists (O'Daniel & Rosenstein, 2008). We really needed that conversation with his team of doctors, or at the very least, just one doctor who could present the whole picture from the team.

I was perhaps excessively worried that if we asked other health care team members for this meeting that we would be judged as nagging and intrusive. At one point, my sister had asked a follow-up question to the pulmonologist, who on several occasions had informed us that he was not only the lead person taking care of our dad, but was also in charge of the whole ICU. In response to her question he said, "I

don't have time to explain advanced biology to you."

This was off-putting, intimidating, and well out of the realm of the ways a patient wants to have communication with their doctor—up to and including their ability to reduce medical jargon (Bendapudi et al., 2006). Fortunately, my sister did not back down, and let him know he could go ahead and give his answer a shot, and that she would muddle through the advanced biology on her own. Probably this would have been the time to remind him that:

"It is the patient who carries the burden of illness, but the compassionate physician shares that burden, lifting it when possible and lightening it when that is all that can be done. This sharing of the burden has always been the hallmark of the medical profession." Richard S. Hollis, MD (Bendapudi et al., 2006).

Doctors' Orders

Though the numerous nurses I met over the twenty-one day period greeted me with varying levels of kindness, there was one consistent theme that I received from them: the doctors put the orders in and the nurses follow them. Evidently, there was little wiggle room for them to make independent decisions about my dad's personal care, and they seemed generally disinclined to question doctors' orders or advocate for a different opinion.

The best example centers around my dad's oxygen requirements. With each nursing shift change came the constant battle of them noticing that my dad's oxygen levels were low and turning them up. I told them that at increased levels, we consistently noticed an immediate decline in his cognitive abilities, including his ability to communicate. Each time I was told that this is standard protocol for a healthy oxygen level for patients.

It took the physicians a long time to figure out, and then write the appropriate orders for the nurses: that in my dad's case, low oxygen readings did not require more supplemental oxygen. His body could not handle it. I would try to be there each time to ask them to refer to this order more closely while I personally turned down the oxygen dose until they

figured it out. This failure of team communication is the most common form of medical errors in hospital settings and is now the third leading cause of death for Americans (O'Daniel & Rosenstein, 2008). The combination of knowing this and my dad's significant mental status changes was so completely unnerving that it made me fearful of everything. I was afraid that I was wrong and that I was making him sicker by intervening in ways that were well beyond my scope of practice. However, my experience with my dad made me feel as if I was right—which made me even more scared. I didn't want to be right. I wanted the health care providers to be right so I could go home and leave them to their job. If I was right and they were wrong, then I had to take responsibility for something that I was not trained to do: basically trying to take my dad's life into my own hands. I felt, and it was confirmed by several events when I wasn't there, that if I left, these details would go unnoticed. I would feel such panic over leaving and would plead with each nurse to make the instructions clear that my dad's oxygen requirements were different from the standard protocol. Sometimes I left feeling relatively assured that the nurse had listened to me, rather than merely having heard me. Usually, I was placated with, "Yes, of course, you don't need to worry. We'll make sure we take care of him while you are gone. You go home and get some much needed rest."

I regularly tell patients that they don't have to worry about something any longer because it is my job to worry about it. Helping patients reduce their worries either by my taking on a role that would reduce their burden, or by explaining things in a more easily understood manner, is a consistent theme in my work. Patients tell me daily that they feel so much better or are less worried after talking to me, which is form of self-reported evaluation I have received over the years to tell me that my services have some value to patients.

But when the nurses told me not to worry, I didn't feel as if they were taking care of it: I felt like my not being there meant that things could go wrong, and they did when the doctors didn't change the oxygen level orders or the healthcare team didn't notice the change and they would subject my dad to oxygen levels that his body could not handle. I would repeatedly come in the next day and find him in a worse cognitive state, again threatened with returning to the ICU again or remaining in the ICU for longer because the standard protocol was being followed for my dad when he

required an exception. His individualized needs were not being met in a system that relies on the routine procedure.

Connecting to the Social Worker

These experiences inclined me to direct questions to the social worker. Part of the job of the social worker is to help people feel that someone is advocating for them, and by virtue of this, it seemed that at least the social worker would be “on my side.” I understood the difficult position I was asking her to walk into. Still: it was important. With the social-worker-as-advocate premise firmly in place, I asked her to please help coordinate my request: That the doctors talk to one another, get consensus about what my dad’s overall status was, then have one of them sit down and talk to us.

Almost as soon as the words started to come out of my mouth, I sensed her resistance; she appeared to feel trapped and filled with dread, her eyes darting back and forth as if looking for escape. She told me this was not a reasonable request, and would not agree to advocate for us. Her tone of voice indicated her incredulity at my presumption. The best she could do was to make a note in the chart that the family would like to talk to the doctors. I was furious, and felt unsupported and out of control. Later the next day, one of dad’s doctors came by and said that he understood that we had questions. My stepmother and I were allowed about five minutes to voice our concerns. It was the last time we were given this opportunity, and my dad was there for another 11 days.

When the doctor left, we still did not have a diagnosis, an intervention, nor a change in medication. We were still met with the answer that other doctors knew more about this or that, and that we would have to speak to each of them individually. I did not ask to see that social worker again, and she never checked back with us to see if we had gotten the answers we needed.

I asked for a social worker’s assistance a second time regarding discharge planning. I was worried that the doctors would suddenly decide that my dad could go home, and that the staff would not have time to get all the things he needed to be there, necessitating transfer to a nursing home instead,

something that regularly happened in my own work. I asked the social worker if she would start working on durable medical equipment (DME) and home care referrals. She was very pleasant and told me she would take the list down to my mother to select which DME and home care agencies she wanted to work with. Although I understood that she was rightly trying to assure self-determination, I told her that she could select those for us because we did not know one from another, and would gladly rely on her expertise to select one. She told me that due to patient choice she would not be able to select for us; we had to do it. I explained that my stepmother had been feeling particularly overwhelmed by all the decisions she’d had to make: whether my dad should go to the ER or not, whether he could come home safely or not, whether he was going to live or not. She went back and forth with me several times, despite my request that my stepmother not be handed this additional decision-making stressor. I felt as though she was deliberately not hearing me, insistent that she would not be able to choose for my stepmother, and offered no other solutions. I quickly called my stepmother to forewarn her and stayed on the phone, acting as a buffer between her and the social worker as the process ensued so that the social worker wouldn’t upset her as she had upset me. Family members have been found to actually experience acute symptoms of PTSD during ICU hospitalizations, especially when they were the primary decision maker, as my stepmother was (Azoulay et al., 2005). I wanted to protect her from as much additional distress as possible.

The third incident occurred around a piece of DME the doctor had ordered for home. It was not just any piece of DME; it was a breathing assist machine, otherwise known as BiPap, which my dad had been wearing ever since he came off of the ventilator in the ICU. The physician told our family that he would have to wear it 24 hours a day or he would die. I contacted the new social worker on that floor to give him a heads-up on what my dad needed so it could be arranged in a timely way. The social worker explained to me briefly that it might be hard to get; I told him I’m sure he would work it out.

A little later my stepmother called me in a panic; the social worker had told her that dad’s insurance wouldn’t let him have the equipment. She wanted to know what were we going to do, and though I had no

idea, I told her I would take care of it and not to worry. If he needed it, he would get it.

Ultimately, the doctors decided my dad would not need the BiPap after all, but my stepmother remained stuck on what the social worker had said to her: that he wouldn't get it because it wasn't covered. I found out later that no one's insurance covers this without having outpatient testing in the form of a sleep study to confirm need. There is some small comfort in knowing that this is how it is for everyone, and that they most likely wouldn't do it that way if people were to die before they got the machine. The point is that no one, including the social worker, explained it to her in that way. What the social worker did not tell her was not to worry, that he would check, that there might be other issues involved that he was not aware of but would look into.

So What does a Social Worker Do?

One day, my stepmother asked me: "What exactly does a social worker do?" She didn't really know the details of my work. She had always heard me say such positive things and had assumed that what social workers do is a great thing. While she had been ruffled by all of my dad's health care providers at one time or another, she had been especially upset by the social workers, as had I. Our experiences were not what any of us thought they should have been. We did not feel comforted. We did not feel supported. We did not feel like someone was advocating for us. We did not feel empathy or validation. We did not feel as if our concerns were being heard.

The social workers told us that we were being unrealistic. They told us that we had to adhere to patient choice about something we did not care to choose, and we were not offered the choice of not choosing. We were told that we would not be able to get equipment the doctor had ordered and said was life saving, and were offered no understanding or other options. Time and time again our experience with the social worker left us more upset than the frustrated reasons we came to them for in the first place.

A Little Knowledge...

I still wonder whether my 17 years of experience in the health care system was an asset or hindrance. Perhaps if I had asked a nurse they would have acted more appropriately. Perhaps my knowledge of how our systems could make such a reasonable request seem ridiculous made me more tentative in my asking, and therefore more likely to meet resistance because of my hesitation. Perhaps the way I, and my colleagues, work in our own particular social work milieu was a unique experience that I should not have expected from other health care providers. Perhaps because I already understood the systems, providers were less likely to advocate for me because they knew that "I should know better," and would have been prepared for the expected negative outcome.

All healthcare providers are potentially susceptible to compassion fatigue, vicarious trauma, and burn out. It comes from being on the cumulative receiving end of patients telling them stories of trauma. Symptoms of these conditions include a lessened sense of safety, control, identity and ability to trust (Bloom, 2003). Perhaps social workers, who are trained to be empathic, client-centered, and collaborative in their approach to patients, are more likely to burn out after being placed in a system that is incongruent with those philosophies. This is not only from patients but the very systems they are required to work within. I myself have certainly experienced periods of exhaustion from fighting the good fight against systems and later realizing that I have less personal resources left available for the families in front of me.

While I knew that it was fair to advocate for my family—and to expect the social worker to not only stand alongside me, but to take the burden for me—I can see that it is yet another barrier that they face with few resources or collegial supports. Based on limited time constraints, I imagine that it might be realistic for them to put me and my family at the bottom of the list, knowing that my family had me to navigate the system for them, when most patients had no one with those skills and resources to offer their patients.

When it works

The fourth and final experience with a social worker was with someone that I did not contact proactively, but who came and introduced himself to my

stepmother when my dad was transferred to a non-monitored bed. This social worker assured my stepmother that he would order all the supplies that she felt they needed for the home and anything the doctor felt was needed as well. He set up a home care agency and an oxygen supply company and came by from time to time to check in and update the family about what was going on over the next several days. On the day my dad was being discharged he came in to fit my dad for the new walker he was supplying us before we left the hospital. My dad rose out of bed to stand next to the walker and promptly passed out right back onto the bed. Of course, we were all in a panic, and though the medical staff took care of him quickly and there was no injury, the social worker stayed in the room and helped my mother and I stay calm. We had assumed he had a seizure, as we had never seen anyone pass out before, and we were more upset than we realized. The social worker stayed long past when all the other clinicians had left the room. With the discharge canceled, my stepmother inquired about what she would have to do to cancel the home care and oxygen people that had just called to confirm they were coming to the house. The social worker said that she didn't have to worry about it; he would take care of it and reorder them when it was time for my dad to be discharged again.

We felt soothed and relieved after every encounter with him. We didn't have to interrupt him to tell him what we were worried about; he was actively listening to us. We did not have to track him down, as he was sure to regularly check on us and inquire as to our needs. We did not have to convince him of our concerns; he was clearly on our side and would proceed with our requests and advocate for my dad's needs. He was empathic, validating, supportive and caring: He was a social worker.

Our experience with him was the first time we had felt safe during the 21-day hospitalization. He did not necessarily have more knowledge, ability or resources than the other social workers or any of the other health care providers we faced; he simply tried harder. He treated us like human beings, perhaps how he would like himself or his family members to be treated.

Other health care providers are often confused by social workers' roles in our systems. We do not

diagnose problems; we assess clients' strengths and resiliencies. We do not prescribe treatments; we give support in building a plan that is based on clients' goals that are realistic, measurable and achievable once they leave the health care setting. They need to be able to implement these interventions into real world settings. If clients feel different, safer, when working with a social worker, it is because we do our job differently: we find out what the individual's goals are and we help achieve them. This is teamwork between the healthcare provider and the patient. This is being client-centered.

Sadly, being client-centered is not congruent with the top-down hierarchy of the medical model. This is not typical of healthcare systems today, and part of why it is hard for social workers to do their jobs in the existing environment. Have some social workers adapted to this culture rather than trying to change it? The history of social work is based on changing the status quo and fighting for social justice. Social workers in complex institutions such as hospitals have to keep this at the forefront of their job even when it seems in total disregard for the rest of the health care team's approach.

Social workers have to make an extra effort to implement other mandates of their profession—advocacy and social justice while continuously working to make a safer and more effective experience for all clients and health care providers. It can be done. I've personally seen it work for my dad and our family.

References

- Auerbach, S.M., Kiesler, D.J., Wartella, J. Rausch, S., Ward, K. R., & Ivatury, R. (2005). Optimism, satisfaction with needs met, interpersonal perceptions of the healthcare team and emotional distress in patients' family members during critical care hospitalization. *American Journal of Critical Care, 14* (3), 202-210.
- Azoulay, E., Pochard, F., Kentish-Barnes, N., et al. (2005). Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *American Journal of Respiratory and Critical Care Medicine 171*(9), 987-994.
- Bendapudi, N.M., Berry, L. L., Frey, K. A., Parish, J.

T. & Rayburn, W. L.(2006). Patients' perspectives on ideal physician behaviors. *Mayo Clinic Proceedings*, 81,(3), 338-344.

Bloom, S. L. (2003) Caring for the caregiver: avoiding and treating vicarious traumatization. In *Sexual assault, victimization across the lifespan*, edited by A. Giardino, E. Datner and J. Asher. Maryland Heights, MO: GW Medical Publishing (pp. 459-470).

National Association of Social Workers (2014). Code of ethics. Retrieved from <http://www.socialworkers.org/pubs/code/code.asp> on November 2, 2014

O'Daniel, M., & Rosenstein, A.H. (2008). Professional Communication and Team Collaboration. In: R. G. Hughes, editor. *Patient safety and quality: An Evidence-based handbook for nurses*. Rockville (MD): Agency for Healthcare Research and Quality (US); 2008 Apr. Chapter 33. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK2637/>

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