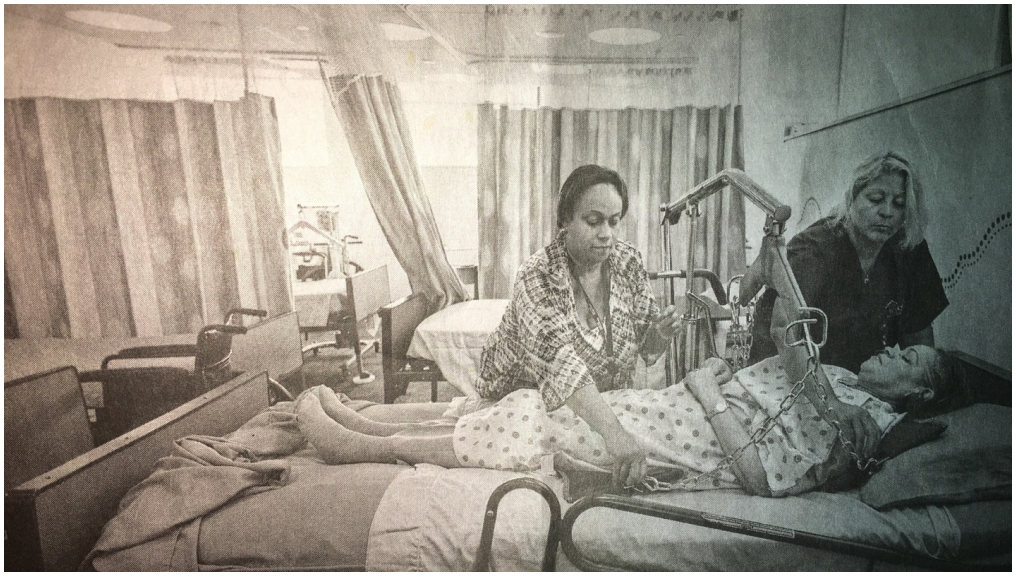
Hidden From Outsiders: Home Care

by Linda Henry



(Image taken from The New York Times **Business** August 30, 2017)

I work in the five boroughs, in private homes, apartment buildings, and on a few occasions in assisted living facilities and nursing homes. Most institutionalized homes are large multistory buildings fully equipped and staffed to provide care for the residents who need long-term care or help to recuperate. Private rooms on each floor accommodate one or more residents simultaneously. The rooms have adjustable cloth screens installed in the roof or ceiling. They provide privacy, especially when the residents are being taken care of by a nurse or doctor, or even during a family visit. Each resident is provided with a bed, chair, TV, closet, chest of drawers and table. Each room has a toilet and sink. Residents who have to be showered are taken to a shower room. The dining areas, recreational facilities, and medical rooms, or clinics, are shared by all residents on their respective floors. These buildings have security desks as soon as you enter them. Persons using the building have to sign in and out, so there is a record of the name, date and time anyone uses the building. I always work one on one with a particular resident that I am assigned to by my agency. My job is to assist the resident whenever my help is required.

Unlike the standard institutional setting, the private homes and apartment buildings vary in size, neighborhood, and safety. Just a few of these buildings have a security desk. The superintendents of the apartment buildings are only visible when there is a need that warrants their presence. These buildings house multiple families, some of whom share the same kitchen and bath. I work with

patients in their homes, helping them with personal care, sometimes with assistance from them or a family member or at other times depending on the situation, alone. My presence in the home also allows family members who are restricted with bed bound parents or children to have some time for themselves. My ultimate goal is to keep the patient clean, fed, comfortable, and safe during my tour of duty. I report any unusual changes in the patient's behavior or illness and any incidents relating to my safety and that of the patients. If required, I would also help with other daily activities, like laundry, shopping and accompanying patients to doctors' visits when authorized by the nurse. My job proves to be both rewarding and challenging at the same time. As a human service major, I get firsthand experience to work with people of different ethnic, cultural, and religious backgrounds, and am able to practice the code of ethics of the agency, which coincides with what I learn in the classroom. Such valued opportunities never come without challenges, but to a large extent, give me the chance to make rational decisions.

One of the many things that I have learned from working in different homes is that many things that seem glorious from the outside are just an illusion. The truth is hidden behind the walls of those concrete or wooden structures, painted or not. The reality is what the family dynamics are and the experiences the patients and their caregivers go through collectively or alone. Socio-economic status, race, culture or educational level for most part does not distinguish their pain and suffering. What may be different is the extent of certain problems that patients go through. At some point some of them come face to face with one or a combination of occasions of helplessness, abuse, and neglect at the hands of close family members, who in some cases even cause them to die before death would occur on its own. This can be painful to behold when there is not much I can do about it in my scope of practice. But sometimes I am tempted to take matters into my own hands to change the pattern of behavior when I feel family members are being unreasonable towards the patients, although of course they have a right to do the things they want to do in the privacy of their homes. Similarly, I have control over what I will accept or not and can remove myself from danger when it is immanent. I have had to make subtle escapes, under the pretense of going to get myself something to eat.

A woman in the building on the third floor saw me standing outside talking on my cell phone and looking up to the building. She presumed I was seeking access to the building and she enquired if I was the aide. She said she was also an aide, and that my uniform was what drew her attention. She opened the door to the building and I made my way up the stairs to the fourth floor. I knocked on the door and a voice from inside the apartment beckoned me enter. I opened the door, which was unlocked and was confronted with the most horrifying scene. I looked around hesitantly to find a

clean spot to put my handbag but there was none. I observed the patient, who appeared to be in his late fifties, displaying a tall frail body, stretched out to full length on a hospital bed, with desperate eyes staring at me. I stepped back out of the door and called the supervisor to tell her of my gruesome discovery. I further told her my first inclination was to leave, but I would not. I knew I could not, not when a lonely sick person needed my help. Supervisor thanked me for the information and for deciding to stay. She said she would communicate my finding to the nurse, immediately. The nurse arrived within half an hour, and experienced the same shock that I had gone through earlier. He too looked around for a safe place for his bag. Luckily, before he arrived I had opened a cardboard box and put my bag on it behind the door. I told him he was welcome to put his there, too, and he was relieved. I remembered all I was saying was, "Oh my God" repeatedly. I could not believe what I was seeing. The patient had soda and juice bottles filled with urine on the floor near the bed, on the fridge, and feces on every piece of bedding on the bed and clothes on the floor. There was no distinction of what was clean or dirty strewn across the floor. There was a commode overflowing with feces, paper and some pieces of clothing in it. I kept saying, "Oh my God", as I tried to clear away the clutter. I was saying Oh my God for more than one reason. There was an aide there the day before, I could not understand. In the meantime the nurse was trying to calm the patient who was cursing hopelessly, I would say. Finally we managed to tidy and stabilize him. The nurse was frantically making phone calls to arrange for the patient to be removed from the apartment to an institution. In between intervals of his calls he was assisting me to clean the room. It took some time before everything was finalized. My three-hour work schedule turned out to be six hours, because I had to wait until the paramedics came, and to close up the apartment after the patient left.

A few months later, I was at another patient's home when the same nurse visited. As soon as he saw me he immediately remembered my name and where we first met, at the home that had so shocked us both. He again thanked me, and said he had told my supervisor what a great job I did for that patient. Then he said, "You know what, that patient died the same night, but the good thing is he died with dignity". Before the patient had left for the institution, he requested that I go to the corner store to get him something to drink, which I did. When I returned with the item he then requested that I go back to the shop to get him a different drink. I told him it was difficult walking up the steps to the fourth floor, but I obliged. During conversations with him I noticed a family portrait on one of the four walls of the room, yes it was just a room. Kitchen and bathroom were located in another part of the building and they was shared by the other residents on that floor. If I can remember clearly, all the furniture he had in the room was the bed, a refrigerator, a center table and the commode. He was short of undies, which were badly needed at the time, luckily a neighbor helped out with that.

Concerning the family portrait, he told me that his wife and one son died a few years prior, and his only surviving son was deployed. At some point I heard him mention God, so I asked him if he believes in God and he said yes, I asked him if he would like me to pray with him and he answered in the affirmative. So I prayed with him. Before he was taken away from his apartment he told me thanks, and that he loved me.

Most of the supervisors are not familiar with the locations where they assign workers. One can tell by the travel directions they give, which are always the longest way rather than short cuts. They do not know the transportation difficulties and other social problems the workers are confronted with in certain areas. Being personally involved in the day to day activities of having direct contact with patients, and using different modes of commute to and from work, helps me to appreciate how much time is sacrificed in order to help patients achieve some level of normalcy in their lives in the comfort of their own homes. Sometimes the travel time is more than the scheduled hours of work. At the end of the day, however, I am privileged to have access to homes that under normal circumstances a lot of people would not. I know what goes on behind many closed doors, and lend a helping hand in the most disgusting circumstances, unnoticed or most of the time under-recognized by those who collect the greater part of the payments for the services we perform in the field. By this I mean, the pay does not match the actual responsibilities and work done for the patients. I still remain committed to what I do, and I have flexible work hours, which allows me to pursue higher education, and have the kind of experience to develop skills to work effectively with patients from different cultures. My access to homes helps me understand the true meaning of family dynamics and the threat to patients' autonomy by their loved ones. But the magnitude of what my work entails is still hidden from outsiders.