

Loss and Grief Due to Chronic Illness: Learning from a Client

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Chronic disease, defined as “...permanent and result(ing) residual disability caused by irreversible pathological alterations in the body” (Megari, 2014, p. 1) effects every aspect of a person’s life in ways that are extremely challenging and overwhelming. The losses connected to it are often too much to handle. Among these are the loss of control, loss of productivity, loss of activities, loss of friends, and loss of self. Many chronically ill patients live in denial of what being “well” means for them; denying that they are now living with limitations (Jackson, 2014). Denial can impede the patient’s ability to reach the point of acceptance, and the path to acceptance can be riddled with anger and depression. Jackson (2014) noted that depression is “normal” in the grieving process associated with chronic illness. It grows into a significant problem, however, when the patient becomes chronically depressed. While a chronically ill patient has the responsibility of maintaining medication levels, dietary limitations, attending regular doctor appointments, and more, feelings of depression can make managing all this an impossibility. The implication of this is that a chronically ill person might begin to neglect their self-care and ultimately risk their health and even their life. In this paper, I will describe an experience working with a client while I was a social work intern at a dialysis center. Ultimately, the client, Sally, taught me some important lessons about working with chronically ill people.

CASE STUDY: SALLY

Identifying Data: Sally is a 65-year-old, African-American female who is divorced and living alone in a condominium. She is the mother of three adult children. She has a son who lives an hour away, and she has very little contact with him. She has a daughter who lives in the same city and helps by

giving rides and visiting with her. Her third child, a daughter, died suddenly in 2013 of a brain aneurysm. She has siblings who live in the area. Her brother is her greatest support. She is very close to him and sees him regularly. In addition, Sally lives in a community where she has been for most of her life. She has a small network of friends and attends a local church.

Presenting problem: Sally suffers from multiple chronic illnesses, including heart disease, diabetes, and end stage renal disease (ESRD). The heart disease requires her to have an internal defibrillator, the diabetes requires her to have an insulin pump, and the ESRD requires her to have dialysis. Sally has had other recent acute health problems that included breast cancer, a broken foot, and eye cataracts.

When she began dialysis, Sally chose peritoneal dialysis (PD) which allowed her to do her dialysis by herself at home. After being on PD for six years, she suffered a systemic infection which resulted in a three-week hospital stay. After recovering from the infection, Sally was required to switch to in-clinic hemodialysis (HD) which meant she had to spend three and a half hours, three times a week in a dialysis clinic. As part of that treatment, Sally needed to have surgery to create a fistula, which is the surgical attachment of an artery to a vein. This is used as a dialysis access point (National Institute of Health, 2014).

The loss of independence and control due to her health problems resulted in significant psychosocial issues for Sally. She had preferred her treatment with PD instead of HD as it allowed her to be independent. While she stated her contempt for the limitations of HD, she recognized she felt better on it and was healthier for undergoing that treatment.

The challenges and stress increase: As time passed, my conversations with Sally grew more personal and it seemed that she was able to work on her psychosocial issues. In the beginning, the meetings served as a general “check-in” about Sally’s health, but after several weeks, Sally began to make mention of her deceased daughter. Still, she did not go into depth about the loss or grief she suffered. She also began to express her frustrations regarding the loss of control in her HD treatment as it required her to rely on medical transportation services and to be in the dialysis clinic for several hours for three days a week. This also complicated her other medical treatments as it meant that scheduling other doctor’s appointments was more difficult. She mentioned her desire to start driving herself the few miles to dialysis, but her daughter had asked her not to until she had her cataract surgery. With all the loss and frustration, at that time, she still had

a positive outlook on life. She worked hard to stay on the bright side of each challenge she faced.

However, two months after we began meeting, Sally entered several weeks of constant stress and frustration. First, she learned she was in the “donut hole” for Medicare, which meant her prescriptions were no longer covered. She had reached her coverage spending limit. She was faced with trying to find a way to avoid the donut hole for the next year, but more importantly, in that moment she needed to find a way to pay for her \$600 monthly supply of insulin. Sally diligently researched her options for changing her insurance plan with Medicare and the prescription coverage for the following year, and she talked to her endocrinologist. The result of her research and conversations was no change to her health plan. The endocrinologist was willing to provide free samples of insulin from his office to carry her through for several weeks until the new insurance year started.

Next, at about the same time, Sally ran into problems with her transportation to the dialysis clinic. A new transportation schedule meant she was arriving to dialysis 15-30 minutes later. She reported having contacted the transportation company to express her discontent. She was told there was nothing they could do; it was the earliest they could pick her up. In a conversation with me, Sally acknowledged the increase in loss of control with the later pickup time and a late arrival to dialysis. Sally said, “I don’t like being dependent on people. I’ve never been a dependent person.”

Then at about the same time, she needed to have several surgeries beginning with her cataract surgery. Although it was successful, she felt very disappointed that her body was constantly failing. Shortly after the cataract surgery, Sally had her fistula surgery for the access point for dialysis.

Then, about the same time, Sally reported that her son-in-law who lived in another state, had just started dialysis. Sally and I were able to discuss the implications of dialysis on a single father. Sally said, “He’s strong and doing well.” I further asked how Sally thought the children were handling their father’s diagnosis and lifestyle change. She answered, “They are tough; they are doing well.” When asked if she would see her grandchildren two states away for Christmas, she replied, “No, it is too difficult for them to come up here.” When asked if she would see her son, she said he would be with his in-laws for Christmas. During a conversation about Christmas, Sally said, “My deceased daughter’s birthday is at the beginning of the year...I know she’s in a better place now.” In these conversations,

despite all the stress and disappointment, Sally worked hard to put a positive spin on some aspects of her life. As the December holidays approached, however, Sally began showing signs of depression which included flat affect, less interest in conversations, and a generally sad demeanor. Her symptoms became noticeable to me and the other care providers in the dialysis clinic. After the Christmas holiday, Sally's fistula was used for the first time. At the end of the first few treatments during which the fistula was used, there was excessive bleeding when the needles were removed. The first use of the fistula was traumatic and very distressing for Sally. The uncontrolled bleeding seeped onto her clothing, and it took an unusually long time to contain the bleeding. Sally felt helpless as she had to remain seated and still after treatment.

Sally wore red for several weeks after that visit as a preventative measure. She was very upset that her shirt had been ruined by the blood stain. She wanted to prevent it from happening again. She expressed anger towards needing a fistula and perceived it as having failed on the first few attempts. It became increasingly difficult to engage Sally. She rarely wanted to talk, and once, as she was leaving, I said to her "I'll see you on Friday?", she replied, "No, maybe you can stop by next week."

Sally did return to the clinic and I worked to engage her, but Sally was despondent. When I asked her "How are you?", she repeatedly said "fine" and seemed to have no interest in talking. I then changed my approach from an attempt to connect by asking questions to simply being present with her, offering her some information or telling a story myself. In the next several weeks, Sally's depressive symptoms increased, and she seemed unreachable. Her doctor indicated that she might benefit from anti-depressants. Still during this time, my long-standing relationship with Sally stayed constant and on occasion she would express her on-going frustration with HD and the loss of control and independence she continued to experience, and she mentioned thoughts of returning to PD.

Eventually, I started to feel defeat and fear that Sally was slipping farther and farther into her depression and out of my reach. Since I am not one to easily admit defeat, however, I researched alternative interventions for working with severely depressed and chronically ill patients. In conversations with Sally, the common themes had been control, independence, usefulness, and helping others. Sally had spoken about her joy of baking, but only to give the baked goods away; her joy of employment and her attentiveness to a high quality of work; her sadness

in not driving and how it limited her life; and her frustrations with having to wait to complete projects until her daughter came over and could help her.

After several weeks, opportunity knocked when a second patient, who suffered from a needle phobia, was scheduled for cataract surgery. It occurred to me that these two patients could help each other; the connection simply needed a facilitator. Sally needed to feel useful and helpful; the other patient needed to feel reassured, certain, and confident. Noteworthy, when I went to Sally, I made the mistake of asking her a usual question, "How are you?" I immediately saw her withdraw upon hearing the question. With my plan in mind, however, I did not wait for a reply, but quickly said, "I need some help, I was wondering if you would talk to me about your experiences with cataract surgery." Sally agreed to the conversation. I said, "This patient has similar health problems as you do. He has diabetes, ESRD, and his cataracts are severe enough that he's almost blind." I explained to Sally that the other patient had been scheduled for cataract surgery, but he had a needle phobia and thoughts of having a knife cut his eye were very distressing to him. I was careful to word my question in a way that would empower Sally and remind her of her strengths. I said, "I am wondering if you can share with me your experience, provide me with some insight, and any thoughts you have that might help the other patient to feel more secure in moving forward with his surgery?" Sally perked up immediately, sat up in her chair, leaned forward, and made eye contact. She then told me about her experience with the surgery. Then Sally went on to offer advice regarding the critical steps of the process. Sally said, "The important thing is that he is not anxious. Being anxious makes you hesitate and think too much. Encourage him to have faith in his surgeon and look forward to being able to see." I said, "This patient's eyesight is so poor. I hope he has the same success with the surgery as you. I remember what you went through and how poor your eyesight had become. He can't watch TV or read." Sally replied, "I couldn't either." With surprise, I said, "I didn't realize your eyesight had gotten that bad." Sally said, "It had, but the surgery has helped so much. I have a prescription for glasses, but I haven't gotten them." I said, "Sally, that's amazing. You're very fortunate." Sally gave her a very meek smile.

Later that day, I shared the information I had received from Sally with the other patient. It helped answer some of his questions as well as identify the aspects of the surgery that still generated fear in him. Remembering the theme of Sally's need to help, I went back to Sally the

following week and thanked her for her help. I let her know how much it helped the other patient. Together we ended up in a lengthy conversation that day about an assortment of topics.

CONCLUSION

Chronic illness and depression walk hand in hand. Sally is still struggling with depression, but as her clinician, I now know the route to take in order to reach her. Sally's path to acceptance is a long one, which is common as acceptance for an ESRD patient on HD is not easily achieved. As one of Sally's cohorts mentioned, it took him two to three years before he settled into the lifestyle change created by HD. As a chronically ill patient, Sally's health is a never-ending cycle of loss followed by healing, which prevents her grief from ever reaching a place of acceptance. Sally is at a higher risk of suffering from chronic sorrow because she remains unable to attain a level of stability with her health, and instead is in a cycle of loss and grief (Jackson, 2014). As a social worker with a goal to help chronically ill patients, especially when they are depressed, I know to listen compassionately and aid the patient through their grief. Sally, however, taught me another important lesson. Everyone likes to feel empowered and sometimes helping others is one way to accomplish this. When Sally could offer information for my other patient, she ultimately began to realize some of her own strengths. It was then powerful for Sally, and for me, as we could "...transform the experience into something livable and bearable" (Jackson, 2014, p. 18).

References

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