

Lived Experiences: Hemodialysis and Adherence

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This qualitative study, entailing face-to-face, individual, tape-recorded interviews with a convenience sample of 22 hemodialysis patients, examines their lived experiences regarding adherence to the hemodialysis treatment regimen. The 7 open-ended questions capture patients' experiences with coming to treatment, taking medications, and restricting fluids. Content analysis identifies the primary patterns in the data—the themes, words, concepts, and terms that prevail in the responses (Patton, 1990). The findings point out the multidimensional aspects of adherence and patient struggles and challenges, and they may open doors for further research that can identify effective interventions.

INTRODUCTION

The questions posed in this study lie within the field of nephrology. What are the factors that influence how a patient responds to the hemodialysis provider's efforts to deliver efficient, effective, life-sustaining health care services, and, at the same time, respect the patient's right to make choices? Although it is expected that patients will do what is required of them to get well or stay alive, often this does not happen for a variety of reasons. People have the right to make choices and sometimes make choices that prove, in retrospect, to be unwise. People sometimes choose not to follow doctors' orders and thus are often labeled "nonadherent." The right to self-determination and the concept of patient choice can and do conflict with caregivers' efforts to deliver prescribed hemodialysis treatment (O'Brien, 1990). This topic is important because nonadherence contributes to mortality and morbidity (Leggat, 2005), increases health care costs (Kimmel et al., 1998), impedes the ability of health care systems to effectively manage chronic diseases (Morgan, 2000), and impacts resource allocation (Atkins & Fallowfield, 2006; Christensen & Johnson, 2002).

Historically, social workers have been the ones called upon to address compliance, which is defined as submitting to a request or demand, and adherence, defined as being attached, devoted to, and supportive of an act or opinion (McKechnie, 1983). In the delivery of hemodialysis services, nephrology social workers are members of a multidisciplinary team that is responsible, along with the patient, for developing a plan of care that is in the best interests of the patient while following the ESRD Survey and Certification Program Guidelines set by the Centers for Medicare & Medicaid Services (U.S. Department of Health & Human Services, 2008).

While respecting the patient's right to self-determination, social workers are called upon to assess, educate, intervene, and assist patients in making informed decisions about their care as part of the care planning process. Knowing the subjective or "lived" experiences of hemodialysis patients and understanding the many dimensions of adherence may enable social workers and the multidisciplinary team to develop effective interventions.

A review of the literature reveals several studies that address adherence to medication regimens, keeping appointments, sharing responsibility for adherence with physicians, the concept of the team approach to adherence, and determining the most effective and efficient treatment regimen. The results are often contradictory. Even quantitative research presents a challenge in identifying factors that influence adherence. A qualitative study conducted in Australia by Williams, Manias, and Walker (2008) addressed the issue of how patients and health professionals view medications and medication adherence. Twenty-three patients with diabetic kidney disease and 16 health care professionals in diabetes and nephrology clinics participated in focus groups. The researchers found that consumers were not convinced of the value and safety of taking their medications and some had difficulty obtaining their medications due to inadequacies in the health care system. The focus of the professionals was on medication adherence. The researchers concluded that the professionals needed to acknowledge the barriers faced by the consumers in order to open up lines of communication that could serve to facilitate medication adherence, promoting the conclusion that patients and health care providers are a team and the providers need to listen to patient concerns.

This researcher perceives a distinction between compliance and adherence as a distinction between the "patient," who is expected to follow the doctor's orders, and the "person," whose medical decisions are made in the context of living life. Compliance research tends to look at the patient (Bame, Peterson, & Wray, 1993; Kaveh & Kimmel, 2001; Morduchowicz et al., 1993; Takaki, Wang, Takigawa, & Ogino, 2007) and paints a portrait of noncompliance based on factors such as attendance, gender, marital status, and interdialytic weight gain as prescribed by doctors. Adherence research tends to look at the person (Gordon, Leon, & Sehgal, 2003; Kugler, Vlaminck, Haverich, & Maes, 2005; Leggat, 2005; Moran, Christensen, & Lawton, 1997; Morgan, 2000; Tijerina, 2006) and ask "why" questions, e.g., "Why are treatments shortened and/or missed?"; "Why do patients not follow diets?"; "Why do patients make the choices they make?" Compliance and adherence research have sought, ultimately, to forward

theoretical frameworks for further study and to create effective interventions to address patients not following doctors' orders.

O'Brien (1990) brought attention to the concept that compliance had no "gold standard" by which it could be measured. She conducted a 9-year longitudinal study that touched on the concept of patient self-determination in which she raised the distinction between ritual and reasoned compliance. She defined ritual compliance as passively following the treatment regimen to the letter and reasoned compliance as active—tailored and modified to meet the physical, social, and emotional needs of the patient (perhaps a forerunner of adherence). Ironically, at the end of the 9 years, O'Brien found that patients who died in the first 6 years had the highest compliance while those surviving the 9 years had the lowest compliance, with both numbers being statistically significant. Patients alive after 9 years reported in open-ended interviews that they had learned where they needed to be strictly compliant and where they could stretch the limits (reasoned compliance).

In a mixed-methods study ($N = 168$), Gordon, Leon, and Sehgal (2003) looked at skipped and shortened treatments, drawing a distinction between reasons for shortening and skipping treatments and general nonadherence. They found that medical problems, life situations, and transportation were the primary reasons for skipping and shortening treatments, and that males and Blacks (males and females) were most likely to skip and shorten treatments. Women reported logistical problems (e.g., child care, family obligations) for shortening treatments and new patients reported technical problems (e.g., transportation) for skipping treatments. These results also support the multidimensional complexity of the concept of adherence.

In a qualitative study ($N = 26$) using phenomenology, a way to look at one's subjective experiences and world view, Tijerina (2006) examined nonadherence among Mexican-American women living in Texas and determined that poverty, length of time on dialysis, immigrant status, perceived identity losses, and family dysfunction impacted adherence. Three years later, she analyzed the same data from a social constructivist perspective, which looks more at the meaning of results, and concluded that poverty, length of treatment history, and whether the patient was an immigrant were factors that appeared to most impact adherence (Tijerina, 2009). Tijerina, a social worker, pointed out that this social constructivist approach facilitates social workers' understanding how these Mexican-American women understood their reality as hemodialysis patients, and that the person-in-environment approach is most effective in working with this population. While Tijerina's results are not generalizable to either women or Mexicans, she provides a viable lens through which patients' lived experiences can be examined.

To frame this study, this writer utilized social constructionist theory as it is defined in the discipline of sociology.

Berger and Luckman (1966) published a classic tome on the sociology of knowledge that introduced the concept of social constructionism. This theory is described as similar to Schutz's phenomenological sociology in which the researcher focuses on the meaning of social experiences (Franklin, 1995). Bengtson, Burgess, and Parrott (1997), gerontologists, declared that social constructionism acknowledges how people create and maintain social meanings in their everyday lives. A "reality" is produced by individual behavior, which then structures people's lives. The message is clear. One cannot understand another's worldview without "walking a mile in their moccasins."

The social construction of diagnosis and medical knowledge addresses the socialization of medical providers, the practices of the health care system, and corporate needs—concepts that are often distinctly different from the interests and reality of patients. Bringing social constructionism directly to the medical field, Brown (1995) described the social construction of diagnosis and illness for providers in three different ways. The first version focuses on how medical sociologists define social problems. Brown's second version of constructionism addresses the issue of medical social control as it is targeted at the human being who is viewed as a potential agent of social action. The social work value of client (patient) self-determination is often challenged as the concept of adherence is vigorously promoted to patients. Brown's third version of constructionism states that scientific facts are the result of scientists' ideas and actions as well as their public efforts to promote their work. The social construction of adherence must be examined from several perspectives. It is socially constructed by patients, physicians, providers, and family members.

While much of social constructionist theory is borrowed from sociology, Witkin (1999) declares that social constructionism is congruent with social work and reflects the values and mission of social work. This congruence obligates social work to lead in translating social constructionist thought into research and practice. He speaks for the patient when he declares "that those who are marginalized in society have a perspective that is valuable for the rest of us to hear" (Witkin, p. 7). The social work profession must be prepared to challenge oppressive social constructions and expose the myth of the "expert professional" who claims to have "privileged knowledge" (Witkin).

METHODOLOGY

This study was conducted in three New York state hemodialysis centers in Brooklyn, the Bronx, and Suffolk County. The qualitative data were collected as part of a larger mixed methods study ($N = 125$) in order to explore in greater depth how adherence is perceived by patients. Seven open-ended questions were asked of 22 patients, a convenience sample, which was chosen based on their willingness to participate. The open-ended questions were included in every fifth questionnaire package and presented to the patients as an additional data collection instrument. However, not

every fifth person was interested. These questions allowed patients to express their lived experiences and their perceptions of adherence and its impact on them, providing their answer to: How do the lived experiences of people on hemodialysis impact adherence?

The study excluded patients who were on home dialysis, under 18 years old, previously on peritoneal dialysis, recipients of failed transplants, incapable of giving informed consent, and incapable of responding to verbal questions. This researcher approached patients at the dialysis centers, explained the study to them, and extended a written invitation to participate. Informed consent was obtained from those agreeing to participate. These documents were translated into Spanish to increase the number of potential participants. A Spanish-speaking colleague obtained informed consent and administered the questionnaire to Spanish-speaking patients.

The 7 open-ended questions were:

1. *Tell me what it is like for you to be on hemodialysis.*
2. *Tell me what it is like for you to come for dialysis treatment and stay on it for the time required.*
3. *Tell me what it is like for you to take all of your medications as prescribed.*
4. *Tell me what it is like for you to restrict your fluid intake.*
5. *Tell me about some of the times that you have been unsuccessful in managing your treatment regimen.*
6. *Based on your experience, what would you tell someone new to dialysis about the challenges of their treatment?*
7. *Is there anything else you would like to say about your experience as a person on hemodialysis?*

Their responses were tape recorded and transcribed by this researcher. The data were analyzed, utilizing content analysis to identify the themes, words, concepts, and terms that were prevalent in the responses (Patton, 1990). The qualitative component sought to categorize the lived experiences of hemodialysis patients as they cope with medication, fluid weight gain between runs, and attendance issues related to the hemodialysis treatment regimen.

RESULTS

This study was designed to capture the lived experiences of people on hemodialysis. The goal of qualitative research is usually understanding, more so than prediction or inference (Drisko, 1997). Understanding what hemodialysis patients experience as they struggle to be adherent is the purpose of this study. The 22 patients answered all 7 open-ended questions. Twelve (55%) of the 22 were less than 65 years of age. Seventy-three percent ($n = 16$) had at least a high school diploma. Twelve were women. The racial/ethnic breakdown was 55% Black ($n = 12$), 27% White ($n = 6$), and 18% Hispanic ($n = 4$). Eighteen had incomes of less than \$25,000 per year. Fifty-nine percent ($n = 13$) lived alone.

Several themes emerged from the data that clearly spoke to the lived experiences of the patients. The most powerful theme to emerge was the challenge of fluid control—not being able to drink as much as they desired. More than half of the patients reported that restricting fluids was hard.

“Very hard, very hard, very hard, very hard, because, sometimes I want some water and I see what place the home attendant is and I hop in the kitchen,” confesses Myrtle, a 67-year-old retired seamstress, about sneaking a drink of water.

“Restricting your fluid is difficult ‘cause you get thirsty,” acknowledges Matt, grandfather of four.

Adam, a young man, admits, “That’s the hardest because sometime(s) you just want to gobble down, drink, drink, drink, and that—that’s the hardest.”

“Very difficult. Um, I love, you know, drinking a very tall glass of cold water and, you know, having to restrict the amount I take in, it’s not something that I enjoy. That I know fluid intake is a big deal in my dialysis treatment so I try, you know. I have to maintain it in order to, you know, have a successful treatment. I’m always thirsty. You know, I feel drained and parched and I don’t like that feeling,” laments Mae, a young mother of two.

Difficulty, frustration, pain, and stress—two-thirds of the patients expressed these themes in their responses. Most realized that hemodialysis is something that must be done, no matter how frustrating or difficult it is.

Says Janet, grandmother of two, “It is very hard, very hard, very hard ...”

“It’s a frustrating situation but you have to live with it,” reports Juanita, a mother of two teenage boys.

For young Simone, whose nursing career came to a halt, “It can be stressful at times. And it’s draining.”

“I don’t like it. It bothers me,” reports Roy, a retired baker.

“Frustrating ... it changed my life completely. I was a career woman, had a wonderful job, doing extra college classes ... an active mom. After I got on dialysis, everything changed. It was all about coming over here, taking care of my health. It’s difficult when all the stuff that you love to eat is no longer something that you can eat,” reports Mae, the young mother of two.

“It’s frustrating ... but you have to live with it,” sighs Judy, a former teaching assistant.

With so much focus on difficulty, frustration, pain, and stress, one may wonder how patients survive. It gets easier with time, a theme emerging from that of frustration.

“At first it was hard, but now I’m getting used to it ...” responds Gabriel, an elderly gentleman who is quite spry.

Matt states, “It’s not easy, but I do it, you know? I just do it. Got used to it.”

Emma, a middle-aged seamstress, says, “It’s not a problem. I don’t complain.”

For Ross, a “young” 84-year-old minister, “No problem. I come all the time. As long as the schedule is set, I’ll be there to meet it all the time.”

The life-sustaining aspect of hemodialysis is evident to patients, despite the difficulty, frustration, pain, and stress.

“If I don’t do my dialysis, then I will die,” concludes Terri, a retired home health aide, who also finds dialysis “very hard.”

“I need it in order to survive,” replies Juan, a Hispanic man with diabetes.

While Mamie, a Jamaican woman, offers, “It’s a blessing for me. I truly need dialysis and I come here with a positive attitude and I try to keep that attitude, and it’s really working out very well for me.”

Ross responds that dialysis is “No problem. I comply with whatever is set for me.”

Aaron, a father of two, says it well: “If I don’t do my dialysis, then I will die. So I just make it good for myself and my kids.”

“Sometimes I feel like I’m, like I’m contained or incarcerated but I got used to it as part of my life’s plan until I get a kidney. I got used to it because I want to stay alive and keep doing what I’m doing,” states Jeff, who still manages to work in construction.

“But, it’s a life-saving—it’s a live-saving—situation. You can continue to do whatever normal things you do, and it’s beneficial to the body and to the soul and for your life,” declares Angel, father of three.

The main theme that emerged regarding living with medications was that taking medications as prescribed was good for them and would help them get better. Secondary themes reflected the ease of taking medications for some patients and the problems encountered by others, such as the number and size of pills, timing phosphate binders, forgetting to take medications, and some difficulty in obtaining medications.

Harriet, a young woman who has had diabetes since age 12, offers, “I take all my medica-

tions as prescribed because, uh, like I said, I want to get better. And that’s going to make me get better.”

“It’s not bad at all. I’m used to it and it makes me feel better,” says Roy.

“It’s not an issue because my medicine is what makes me get better, so if I don’t take it, I get sick,” affirms Natalia, a young Hispanic mother of two.

Seven reported that taking medications was easy, no problem.

“Natural and easy. I do it every day. No problem with that,” announces Ross.

“Oh, it’s not a problem taking the medicine. I just take them, you know. It’s like it’s set in my head, you know, like clockwork and I just take them,” reports Aaron, father of two teenage boys.

Five of the 12 patients pointed out some of the problems they encounter in taking their medications.

Mae, reports, “Frustrating. It’s hard, you know, sometimes, to remember, um, ‘cause I take a lot of medications, so, it’s not something I enjoy ...”

“My problem is the renagel. Don’t tell them, but I never take it. [laughs] The rest of the stuff I take,” confesses young Adam.

“I take 35. I counted them once,” laments Roy.

Many dialysis patients experience some barriers, obstacles, and problems. While some are simply overwhelmed by the whole experience, others have specific challenges that they have encountered—some more serious than others. While 9 patients flatly denied having any problems (e.g., “None, at no time,” “I never had a problem,” “No, not at all,” “Well, thank God, in the two years I’ve been on dialysis I haven’t had no problems and I’ve been doing great.”), many patients did express that they have encountered problems that caused them great concern.

“The holidays, weekends, office parties ... you know, regular home parties,” laments Queenie, a clerk, about events made difficult by her condition.

“Oh Lord, sometimes in the morning I get up and I stick my finger. I like to see my sugar in the ones but when it gone up in[to] the twos and threes, I got the cold sweat[s] and I shake and I shake,” cries Myrtle.

“Oh, yes, a few times I hadda have the fistula; I had to get a balloon blown up in the fistula,” Matt complains.

“Well, there are times when my body starts to itch. Well, I guess that was because my phosphorus level was rising,” reports Juan.

“Well, just this week here itself, I’ve been having a lot of low blood sugars. It was two days out of the week that I wasn’t able to wake up and I thank God for my sister being home, that she was able to call the ambulance to come and help me out because the sugar level just dropped low regardless of what I did,” laments Harriet.

“Maybe—when I first started dialysis and I had a tube coming out of here and I went to the gym and went swimming and I almost died. And my body, was, you know, had chills and stuff and I had to go to the hospital,” confesses Jeff.

“Oh! The only problem I ever had was when I was working, trying to go to work and be on time and still, still [had to] come here for all the hours,” declares Gus.

The lessons learned by hemodialysis patients are many. These are lessons that allow them to advise new patients to help them avoid some of the pitfalls. Patients are only too willing to give advice, another emerging theme. The advice that they would give to patients new to dialysis covered a wide range of subjects. Eleven patients pointed out urgently that dialysis keeps one alive.

“Please, just come with a positive attitude. Know that this dialysis is going to help you and continue to let you live for however long. If you do what you are supposed to do, dialysis can be very successful [for] you,” declares Judy.

“Keep your head up, hang in there. Not as bad as what you think—life still goes on, you know. And just look at all the positive ways that you still are here. You could be gone,” advises Emma.

Eight subjects advised new patients to go to their treatments.

Adam muses, “What can I say? I’d feel sorry for the guy. For one thing—what else can I say, you know? Just that—sit back and take your treatment. That’s all, you know.”

“Just tell them make sure they go to their treatment and try not to skip none. Listen to the doctor and just go to your treatment,” warns Aaron.

Simone says, “First of all, you have to go, even though you don’t want to go, but you have to go, because, you know, it’s going to help you. Just be patient, that’s all.”

Four pointed out that it is hard.

“I would tell them it’s not easy, it’s hard, but to stay on their daily regimen and never cut their time,” cautions Janet.

“It’s difficult when all the stuff that you love to eat is no longer something that you can eat. You just have to make the sacrifice to deal with the change,” laments Mae.

Three cautioned about fluid restrictions.

Myrtle declares, “Stick to your treatment and stick to your diet. I can’t tell them nothing else. Stick to your treatment. And don’t drink too much fluid ‘cause when you get on that machine and start getting cramps you call [out] a lot of bad words.”

Coping strategies were the focus of patients who sought to assist others to adjust and survive. Six subjects addressed their efforts to restrict their fluids, offering suggestions.

“It’s not easy during the summer, but it’s necessary, ‘cause I don’t want to go forward one and take two steps back. So my fluid intake is very important to me. No problem, you know. Just eat a lot of ice instead of drinking fluids. Just munch on some ice. It’ll last you longer and, you know, it quenches your thirst,” offers Juan.

Matt has found a system. “Well, in the summertime, and I get thirsty, I have an old juice jar. I think it’s about six ounces. That’s how I measure my drink.”

“Oh, I’m good at that. I’m very good at that. When I’m thirsty, I suck on ice,” boasts Harriet.

DISCUSSION

The lived experiences of the hemodialysis patients in this study reflect the many dimensions of adherence. Being on hemodialysis and coming for treatment is hard, frustrating, challenging, as well as life sustaining. Medication adherence is contingent upon remembering to take it and having the medication. Restricting fluid intake is hard. Sucking ice and measuring fluid help control intake. Some of the reasons for unsuccessful management of the hemodialysis treatment regimen include: poor attendance, itching, uncontrolled glucose, catheter infections, work, holidays, and weekends.

Twelve of the 22 patients responded that they took their medications because they were good for them and would make them better. Williams, Manias, and Walker (2008) point out that many patients doubt the safety or effectiveness of their medications, which was not the case with this sample. Among the problems raised were: remembering to take medications, an issue addressed in a study by Atkins and Fallowfield (2006), the number of pills prescribed, and, specifically, the phosphate binders. Two patients admitted that they did not take their phosphate binders. The 7 patients who reported no problem with taking their medications described it as a part of their routine. They had accepted it as part of their lives.

The results regarding fluid adherence reflect the struggles many patients face, along with the good feelings they have when they succeed. Thirteen of the patients reported that restricting fluids was hard. They were always thirsty and felt parched, drained, and deprived. Only 4 patients

reported that restricting fluid was not hard, 3 of whom cited the dire consequences of fluid overload, a reflection of Yokoyama et al.'s (2009) results that people who believe that benefits outweigh barriers are more adherent to fluid restrictions. Six patients addressed their efforts to restrict their fluids, offering suggestions such as sucking ice and using a 6-ounce glass to measure fluids.

Thirteen patients reported that they are used to coming and staying for treatment, and found it was not a problem. Nine found it hard, and 5 simply stated that hemodialysis was what kept them alive so they came. Several of those who found it hard also acknowledged that it kept them alive.

Kaveh and Kimmel (2001), continuing to pursue a "gold standard" (a way or ways accepted universally by which to measure adherence), proposed total time adherence as one measure of treatment time adherence. This researcher opted to utilize this measure as it captures the composite concept of attendance, which had formerly been broken down into skipped and shortened treatments, two distinctly different concepts (Kimmel et al., 1995).

The limitations of this study lie in the small sample size and lack of generalizability. Another limitation may be the influence of the interviewer on patients' responses, always a factor in qualitative studies. Future research can include repeating this study with a larger sample that incorporates a wider range of demographics—additional ethnic groups, rural communities, people who speak languages other than English and Spanish—which could yield results that could provide additional strategies to enhance adherence. This study looks only at in-center hemodialysis patients. Studying peritoneal dialysis or home hemodialysis patients could yield very different results. A quantitative study could look at the issues identified in this study to see if they are predictive of nonadherence. In the context of social work and the National Association of Social Workers (1996) Code of Ethics, knowing more about the lived experiences of hemodialysis patients can facilitate the design of effective interventions. Both seasoned and novice nephrology social workers can benefit from the results of this study. Focusing on the lived experiences of in-center hemodialysis patients, along with the standard assessment forms currently used, can provide a richer picture of the person who is the patient. This can facilitate "buddying," support group formation, and general patient education, leading to effective interventions to address nonadherence.

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