Negotiating Living with an Arteriovenous Fistula for Hemodialysis

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End stage renal disease (ESRD), a chronic condition requiring complex, technically oriented, expensive care, is a public health problem that is over-represented in minority, low-income, and elderly populations. In 2007, 526,343 clients in the U.S. had ESRD at a cost of $23.9 billion dollars (U.S. Renal Data System [USRDS], 2009). At the start of 2008, approximately 367,604 clients in the U.S. were on dialysis, and most of these, 341,264, received hemodialysis (USRDS, 2009).

A vascular access is required for hemodialysis, and an arteriovenous fistula is the medical access of choice because it has a longer patency rate, has fewer complications, is more cost-effective, and is associated with less mortality than other vascular accesses (Centers for Medicare & Medicaid Services [CMS], 2004; National Kidney Foundation [NKF], 2006; USRDS, 2009). The CMS (2006), NKF (2006), and Healthy People 2010 (U.S. Department of Health and Human Services [USDHHS], 2000) set the goal of 66% of prevalent clients and 50% of new clients to have a fistula.

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The purpose of this study was to examine how clients with end stage renal disease on hemodialysis negotiate living with an arteriovenous fistula. A fistula is the preferred access for hemodialysis, and clients must continually monitor and protect their fistula. In this qualitative, ethnographic study, data were collected during fieldwork and semi-structured interviews. Constructivism and a cultural negotiation model provided frameworks for the study. Fourteen clients were interviewed; interviews lasted 1.5 to 4 hours. Results revealed new insights into informants' perspectives and experiences with a vascular access. The overarching theme was vulnerability, and underlying themes were body awareness, dependency, mistrust, and stigma. The response to vulnerability was to be continually vigilant and assertive to protect the holistic self. Stigma of the vascular access was an important issue for informants and evoked the greatest emotional responses.

Goal

To provide an overview of clients' vulnerability as based on their body awareness, dependency, mistrust of the healthcare system and providers, and stigma as the result of their fistula.

Objectives

1. Explain the purpose and care of a fistula in hemodialysis treatment.
2. Discuss how clients may feel vulnerable as the result of having a fistula, based on the results of this study.
3. Identify examples of how clients may elicit feelings of dependency, mistrust, and poor physical self-esteem by having a fistula.
4. Describe how nephrology nurses can assist clients who are on hemodialysis and requiring a fistula with their feelings of vulnerability.

Establishing and maintaining a vascular access is one of the biggest problems in hemodialysis (Bonello, Levin, & Ronco, 2004); 20% of hospital admissions for clients on dialysis are for vascular access complications, with an annual cost to Medicare of over one billion dollars (Saran, Pisoni, & Weitzel, 2004). Although fistulas are preferred over grafts or catheters, the client must continually monitor the fistula because its care and protection are integral to the fistula's survival. However, these activities have not been systematically studied from the client's perspective. This

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qualitative study examined the experience of clients with ESRD on hemodialysis negotiating living with a fistula.

Background

Conceptual Framework

A qualitative approach permits understanding the client's illness experience. An ethnographic approach generates explanations of how people think, believe, and behave (LeCompte & Schensul, 1999). This approach engages the researcher and informant in dialogue that exposes the informant's views, perspectives, and construction of an experience. Constructivism is interpreting one's reality from one's perspective, experiences, values, beliefs, and culture (Lincoln & Guba, 1985). Because the informant and researcher are co-creating the data and interpretation (Lincoln & Guba, 1985), the researcher continually validates the informant's responses during the interview and integrates reflexivity.

Engebretson and Littleton's (2001) cultural negotiation model provides an additional framework that situates the client within the cultural worlds of the healthcare system, as well as within local and general cultures. Anthropologists have described the healthcare system as a unique culture (Lock & Gordon, 1988). The model, designed for nursing practice, is adaptable to research, and it recognizes that informants are active participants in the management of their chronic conditions. The informant and researcher have a relationship and interact from their cultural perspectives, termed cultural negotiation. Each person brings attributes of cultural heritage, personal experiences, formal/informal knowledge, and personal knowing to the interaction (Engebretson & Littleton, 2001).

End Stage Renal Disease and Treatment

This study addresses a vulnerable population at a very precarious time. ESRD is defined as less than 15% renal function, inability to maintain homeostasis, marked fluid overload, electrolyte imbalances, retention of nitrogenous wastes, and development of an uremic syndrome (Richard, 2001). ESRD is treated with renal replacement therapy – kidney transplantation and/or dialysis.

Hemodialysis is a technical procedure conducted extracorporeally and requires special equipment. Typically, three types of vascular access are used for long-term care. In the U.S. in 2007, 50% of prevalent clients had a fistula, 31% had grafts, and 19% had catheters for hemodialysis (USRDS, 2009). A fistula is created by surgically joining an artery and vein, a graft is created by surgically implanting a tube-shaped substance between an artery and vein, and a catheter is inserted into a large vessel. The fistula and graft are subcutaneous, whereas the catheter protrudes from the skin.

A fistula is a configuration that results in arterial blood flowing into a vein that subsequently becomes arterialized. A fistula takes approximately one to four months to heal and mature before it can be used for hemodialysis (Besarab, 2004). As the fistula matures (or the vein arterializes), the vein becomes engorged, thickens, enlarges, and is readily visible on the skin surface as a substantially raised area. Arm exercises, such as squeezing a rubber ball multiple times a day, enhances maturation of the fistula (NKF, 2006; Oder, Teodorescu, & Uribarri, 2003). Two studies have shown a significant increase in venous vessel size after arm exercises (Leaf, Macrae, Grant, & Kraut, 2002; Oder et al., 2003). A larger vein has a larger blood volume and flow that are necessary for hemodialysis. A fistula is mature when the vein has arterialized, is accessible for safe-cannulation (close to skin surface), and is large enough to tolerate high blood flow rates of 500 to 600 ml/minute (Allon & Robbin, 2002; NKF, 2006). In hemodialysis, the fistula is cannulated or venipunctured usually with two large 14 to 16-gauge needles. Blood leaves the body via one needle and returns to the body via the other needle.

Once the fistula is created, clients must continually monitor, care for, and protect it. Clients need to become familiar with their fistula so they can detect slight changes. The American Nephrology Nurses' Association (ANNA) (2006), CMS (2004), Fistula First (2006), NKF (2006), and the Vascular Access Society (n.d.) recommend that clients complete a circulatory, neurological, and muscular assessment of the fistula and extremity. Feeling for pulses and a thrill (vibration) around and over the fistula, respectively, assesses blood flow and patency. Although research has not established an optimal frequency for these assessments, Berman and Gentile (2001) found that assessments led to early detection of problems, especially clotting and/or stenosis, and enhanced early treatment and the likelihood of maintaining a functioning fistula. Clients should keep the area clean and assess for infection. Additionally, the extremity must be protected from pressure and injury, which could compromise fistula function. Thus, clients need to avoid restrictive clothing, blood pressure cuffs, venipuncture (other than for dialysis), lifting heavy objects, and prolonged bending of the extremity. The contralateral extremity should also be protected in case a vascular access needs to be created there (Allon & Robbin, 2002). The client's self-care of the fistula is integral to its functioning, and yet these activities have not been systematically studied from the client's perspective.

Research on Self-Care Behaviors

For clients with ESRD, daily self-care includes managing a complex treatment regimen of vascular access care, fluid limitations, medications, and dietary restrictions (Richard, 1986, 2006). Self-care management encompasses compliance and adherence, and advocates clients be partners in their treatment, have the knowledge and skills to care for themselves, make decisions about their care (Aujoulat, Luminet, & Deccache, 2007; Evans, Wagner, & Welch, 2004; Thorne & Paterson, 1998), identify problems, set goals, and monitor and manage symptoms (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Holman & Lorig, 2000; Schreurs, Colland, Kuijer, Ridder, & van Elderen, 2002). In a metasynthesis of qualitative studies since 1980, Thorne and Paterson (1998) found that patients reported a change in perspective of their chronic illness; they went from a dependent, suffering, sick role to finding health, transformation, and positive aspects of chronic illness and being a partner in one's care. A qualitative study of clients with ESRD on hemodialysis by Curtin, Mapes, Petillo, and Oberley (2002) reported similar findings.

After a literature review of self-care with ESRD research, Richard (2006) concluded that a definition of self-care for the ESRD population on hemodialysis is evolving. Although studies on fluid, dietary, medications, and client perspective of self-care were found, only one study focused on vascular access care. Brantley, Mosley, Bruce, McKnight, and Jones (1990) divided the sample ($n = 56$) into four groups: education, behavioral, education with behavioral, and attention control. Brantley et al. (1990) found the three groups that received vascular access cleaning education showed a significant increase in vascular access care knowledge. The two groups that interacted with the research staff (behavioral) showed a significantly higher completion of vascular access cleaning immediately after the intervention and one month later. Proper vascular access cleaning, however, was not evident one year later. Even though education increased knowledge, subject-staff interaction was necessary for subjects to successfully implement vascular access cleaning. Useful results could be obtained from measuring vascular access cleaning knowledge and procedural care at regular intervals throughout the year that could be used to design studies for intervention reinforcement.

Client's perspectives influence implementation of self-care. Curtin and Mapes (2001) interviewed 18 informants who had been on dialysis for at least 15 years. Overall, the informants managed both health professionals and the healthcare system to receive the best care. They used six major strategies: 1) a careful presentation of self so as not to anger the staff who might withhold care, not respond to emergencies, or harm their vascular access; 2) listening to their body and selectively reporting symptoms that needed attention; 3) scrutinizing all treatments to be sure they were conducted carefully and correctly; 4) being knowledgeable about treatments and procedures, and suggesting changes and/or alternatives diplomatically to professionals; 5) being a self-advocate when necessary; and 6) implementing non-prescribed therapies to meet health needs if unable to get them met via professionals and the healthcare system.

Client Perspective of Vascular Access

A paucity of research explores the experience of having and maintaining a vascular access from the client's perspective. Clients and clinicians have informally reported a number of issues that have not been systematically investigated. Clients and professionals refer to the vascular access as a life line (Levy & Wynbrandt, 1975; Merrill, Brouwer, & Briones, 2005; Newmann, 2004; Richard, 1986). These accesses require surgery and often many de-clotting and revision procedures. The loss of a dialysis access has a significant impact on the psychological environment. Clients have feelings, emotions, and a perspective about their vascular access (Levi, 1984; Reichsman & Levy, 1972; Rosen, 1999; Weldt, 2003), and how personal experiences influence vascular access function and longevity need to be studied.

Newmann (2004) solicited comments via a dialysis patients' listserv from clients on hemodialysis about their vascular accesses and asked them about important points to share with hemodialysis staff. The voluminous response to Newmann's request suggests that clients are eager to discuss their experiences, willing to put forth the extra effort to write about them, share their stories, and learn of others' experiences. Even though Newmann's work was not a scientific, formal study, the anecdotal reports suggest topics that need further exploration and explanation. Respondents expressed many concerns about the staff; they wanted staff to listen to them, be aware of their needs (emotional), respect their access, use sterile technique and careful venipuncture with each cannulation, offer education about self-cannulation, and be consistent with instruction about access self-care.

In summary, ANNA (2006), CMS (2004, 2006), Fistula First (2006), Healthy People 2010 (USDHHS, 2000), and the NKF (2006), as well as previous research, have focused on the physiological, anatomical, surgical, and technological aspects of vascular access with very little focus on the client's human experience of vascular access. Hence, a major gap in the nephrology literature and community is the lack of research on the ESRD client's perspective and experience of a fistula or vascular access for hemodialysis.

Methods

The university's Institutional Review Board approved this qualitative, descriptive, and ethnographic study. Ethnography investigates the cultural orientation of people's cognitive constructions, values, beliefs, and behaviors (Geertz, 1973). Groups of people with a common condition or illness develop some shared cultural experiences of living with that condition and interacting with the healthcare system in managing their illness (Kleinman & Seeman, 2000).

Sample

Inclusion criteria for the interview informants were that they be 22 years of age or older, willing to participate in the study, and able to understand, read, and speak English. Informants had a fistula at the time of the study or in the past, or were scheduled for placement of a fistula. Purposive sampling was used to recruit informants who were articulate responders and provided rich information (Patton, 1990). Rich information or thick descriptions provided details, specifics, and the context in which an event or behavior occurred and differentiated between seemingly similar events that are really different events when explored in-depth (Geertz, 1973). Purposive sampling was also used to select informants that represent the sociodemographics of the ESRD population and who had fistulas for varying lengths of time and degrees of maturity and function. Sampling continued until redundancy occurred with data saturated and no new themes identified.

The sample represented variation in age, gender, ethnicity, education, marital status, etiology and treatment for ESRD, and type of vascular access. Fourteen informants with ESRD were recruited through health care professionals. Sample demographics are shown in Table 1. Informants' ages ranged from 23 to 87 years (mean = 59). Genders were equally distributed among ethnicity: with two men Hispanic, two Black, and three White. Of the seven women, three were Black, and four were White. One man worked part time as a yoga instructor, and the other participants were unemployed or retired. One informant completed 10th grade, two high school, five some college, four a baccalaureate degree, one a masters, and one a doctorate. Eight were married or with partners, two widowed, and four single. Etiology of ESRD varied as follows: nephrotoxins (3), diabetes mellitus (2), hypertension (2), cystic or polycystic kidney disease (2), unknown (2), poststreptococcal glomerulonephritis (1), chronic kidney infections (1), and renal artery obstruction (1). All renal pathologies occurred over time and primarily affected the renal vasculature or nephrons. Two informants were born with one kidney, and four had a kidney transplant. Average age for beginning dialysis was 51, with a range of 17 to 87 years. Thirteen informants dialyzed four hours three times a week, and one person 2.5 hours six days a week. Most informants had a history of several types of vascular accesses associated with many surgical procedures. Nine informants had had a fistula, and five still had one. Three informants underwent surgery for fistula creation, and the fistula was unsuccessful for anatomical reasons. Although two other informants were scheduled for creation of a fistula, they changed their minds and refused because of the appearance of the fistula and the pain of cannulation.

Table 1
Demographic Data (n = 14)

Variable	
Age	
Range 23 to 87 Years	Mean = 59 Years
Variable	**Frequency**
Gender	
Female	7
Male	7
Ethnicity	
Black	5
Hispanic	2
White	7
Highest Level of Education	
Less than high school	1
High school	2
Some college	4
Associate degree	1
Bachelor's degree	4
Master's degree	1
Doctorate	1
Relationship Status	
Married	7
Single	4
With a partner	1
Widowed	2
Employment Status	
Part-time	1
Unemployed/retired	13

Data Collection

Consistent with an ethnographic approach, data were collected through interviews, field notes, documents, and artifacts. Fourteen informants were interviewed – 12 at their homes and two in private offices (their choice). Informants were eager to talk, and interviews lasted 1.5 to 4 hours (mean = 2.75). The informants were observed during the interview for fatigue, such as a dry mouth, slow speech, and drooping body posture, and they were asked several times if they would like to stop and/or continue another time. They were loquacious about their vascular access and dialysis experiences, and provided thick descriptions.

The interviews were structured according to Spradley's (1979) classic approach of using open-ended general (grand tour) to more specific (probe) questions. Although an interview guide was used to assure a systematic approach to data collection, it still provided flexibility in the sequencing of interview questions.

After the informant signed an informed consent form, the data collector turned on the audio recorder. Each interview began with completion of a demographic information form, which prompted some informants to discuss relevant topics. If not, they were asked a grand tour, descriptive question, such as "I understand you began dialysis. Tell me about that." Whatever word(s) the informant used regarding kidney disease, dialysis, fistula, or other topics were subsequently used by the interviewer. Restating the informant's words helped to establish rapport and decreased possible anxiety that the informant had about saying the right thing (Spradley, 1979). Restating the informant's words also demonstrated that the interviewer was listening to the informant, valued his or her words, and provided an opportunity to clarify the meanings. They were asked comparison questions, such as, "How does your fistula feel before dialysis, during dialysis, and after dialysis?" As the informant discussed a topic and richer information was needed, the interviewer restated the informant's response and then used a probe, such as, "You said you do __ for your fistula, is there anything else you do for your fistula?" Further, throughout the interview, the interviewer repeated the informant's narrative with interpretation for clarification and validation.

Fieldwork

Fieldwork included taking field notes, identifying artifacts, and making observations in dialysis and vascular access facilities. Immediately following an interview, detailed field notes were recorded systematically in a specific notebook. Field notes included a description of the interview environment, who was present, a description and/or drawing of the fistula or other vascular access, changes made in the home, products or artifacts used because of the fistula, body language/gestures and impressions that added meaning to the informants' spoken words, and future issues/topics to pursue with the informant or in fieldwork. An interview summary form that encapsulated the main points was also completed. Fieldwork included examining and/or obtaining informational resources that informants discussed in the interviews, such as Internet sites or written materials. Any documents that the informant gave or that were obtained by the interviewer were labeled, attached to a document summary form, and placed with the informant's other written materials. Likewise, any artifact that the informant described or demonstrated was recorded on an artifact summary form. After each interview, reflexive notes were recorded in a separate journal that included information about the interviewer's thoughts, responses, and experiences with the interview, and how these might have influenced the interview and eventually data analysis (Dowling, 2006). Fieldwork also included observations in several dialysis and vascular access facilities to observe the context and process a client's experiences with vascular access. Following these observations, detailed field notes were recorded systematically.

Data Analysis

Data from the demographic-information forms were tabulated using descriptive statistics. Information about vascular accesses (such as type, location, length of time since created, condition, and length of time used) were also described.

Data analysis was a nonlinear, iterative process involving data collection, reduction, display, and interpretation. According to Miles and Huberman (1994), data analysis began with the first informant, and continued with each interview and into the development of this article.

A professional transcriptionist prepared the transcripts verbatim. The researcher verified the written transcripts by listening to the audiotaped interview as the transcript was read and made corrections. Then information from field notes was incorporated into transcripts, memos were written, an audit trail was maintained, and reflexive notes were recorded. This resulted in approximately 1000 pages of scripts and information.

A data display in the form of a three-column table (matrix) (Miles & Huberman, 1994) was created with the informant's words in the left column, codes in the center column, and categories in the right column. A code was a name/label that assigned meaning to a segment of related data (Miles & Huberman). Once the transcript and codes were entered into the matrix, relationships among the data surfaced. As the interview and matrix were reread, the data display was rearranged and reduced, categories were clustered together, and potential themes became apparent. Simultaneously, a code book was created, memos were written about the rationale for decisions, and an audit trail maintained. Another data display in the form of a thematic schema was created that depicted linkages between themes. Multiple debriefing sessions were held with other qualitative researchers and data displays redrawn until one triumphed (see Figure 1).

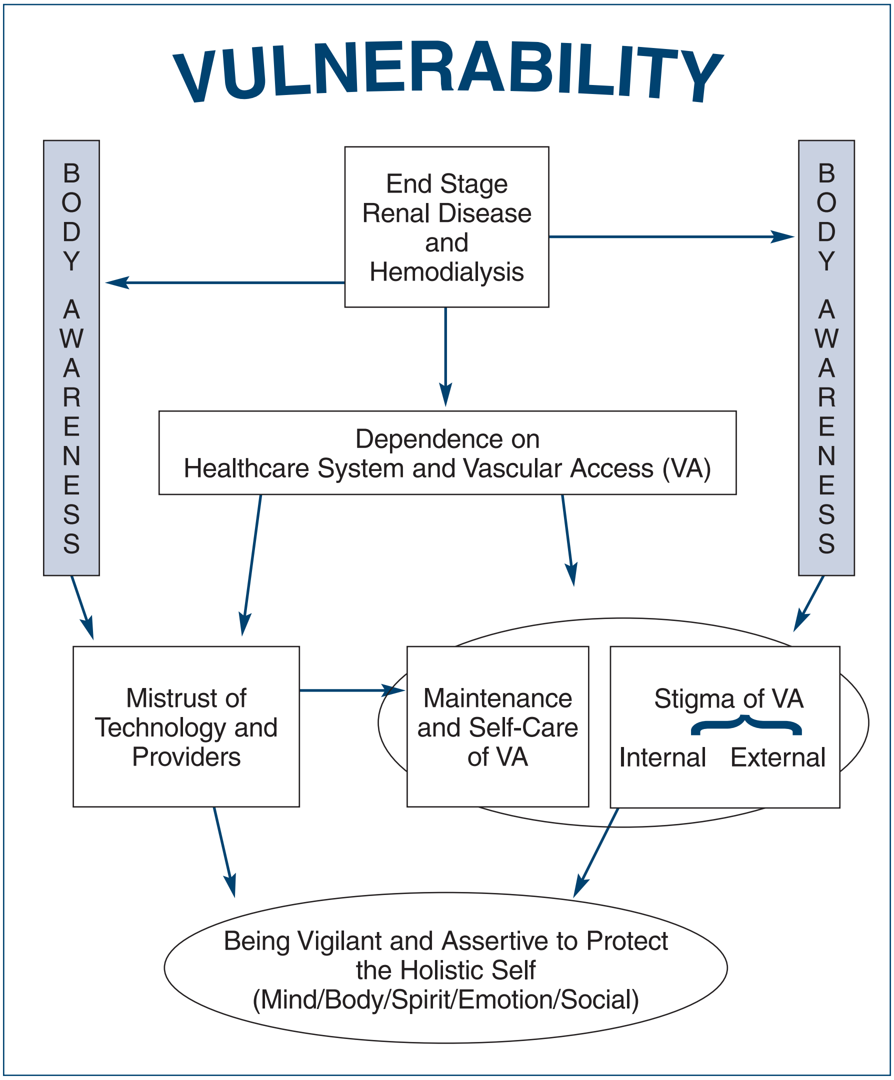
Trustworthiness

Trustworthiness (Lincoln & Guba, 1985) includes credibility, confirmability, reflectivity and reflexivity, and applicability. This study employed strategies to assure trustworthiness and credibility. By spending time in the field, vivid descriptions were gathered that represented the informant's experiences. The length of the interviews and the willingness of the informants to describe in detail their experiences contributed to credibility. Purposive sampling recruited informants with variation in demographics, experiences with a fistula, and other accesses. This assured a broad perspective of the phenomenon of living with this condition. Data were validated with the informants during the interviews to assure that the author interpreted their narratives correctly. Confirmability was enhanced by peer-debriefing sessions that employed a critical dialogue with a group of qualitative researchers, and doctoral students and faculty that challenged the interpretation and analytic process. An audit trail was kept that outlined decisions made regarding data analysis (Schwandt & Halpern, 1988). Finally, a continual process of reflectivity and reflexivity was utilized to critically examine the data and the process of conducting the research (Finlay & Gough, 2003). The findings are presented with sufficient data for readers to evaluate applicability to their setting or population.

Findings

The purpose of the research was to examine the experience of negotiating living with an arteriovenous fistula for hemodialysis. The overarching theme is vulnerability and an underlying theme is body awareness (see Figure 1). Vulnerability is based

Figure 1



Note: VA = vascular access

on having ESRD, requiring dialysis, and being dependent on the healthcare system and the integrity of a vascular access for survival. This dependency creates a situation that often leads to mistrust of the healthcare system, both technology of hemodialysis and providers (for example, nurses and physicians), and the need to cope with maintenance and stigma of the vascular access. The response to vulnerability was to be continually vigilant and assertive to protect the holistic self. This article focuses primarily on the findings related to vascular access in the context of ESRD and hemodialysis.

End Stage Renal Disease, Hemodialysis, and Body Awareness

Informants beginning to experience the signs and symptoms of ESRD notice persistent bodily changes that are unexplainable and untreatable with methods from their previous experience and knowledge. These bodily changes motivate informants to seek professional help. The following stories were typical of most informants' experiences about their increased body awareness of ESRD, what they ultimately did about it, and their vulnerability to the unknown.

> *I was getting weird bruising on my body, like very strange bruises would pop up...over night... Then I got weaker and weaker, and weaker, and I went to my doctor, and I said, 'I am not exactly sure what I have got, but I know it has got to be serious,' and I said would you please do some tests and see what is going on.*

> *...The way it started with me, I began to urinate a lot and I didn't know why... So after the urinating, I started getting something like the flu, like a cold. I thought it was just normal, just a seasonal thing... That is when I saw the doctor.*

Some informants noted improvements in their bodies after beginning hemodialysis and a lessening of the signs and symptoms they had before the diagnosis of ESRD. In addition to a cognitive understanding for the need of hemodialysis as presented by the physicians, their body awareness confirmed the need for treating ESRD. The informants quoted below felt relief that hemodialysis was able to help them and decrease their vulnerability to dying. Both were close to death before they received their first hemodialysis treatment.

> *...Since dialysis, my health symptoms have improved. Well, number one, I haven't had any more episodes of shortness of breath...[related to pulmonary edema].*

> *When I got home that evening [after first hemodialysis treatment], that was a big difference at what I felt. I mean, I felt relieved. All the fluid and all the toxins [were] out of me.*

Within a few treatments, informants recognized that their bodies were responding to hemodialysis, even though they did not know exactly what was happening.

> *...when I had my first dialysis...I felt a little cramped in my fingers, but it was mild, I didn't know what it was, but other than that I had no feelings... Now the second day...that is when I first had any feeling. I didn't know what was going on. I didn't even know what the feeling was...so when I called the nurse and said you know I feel funny because I was reading and my vision was blurred...*

> *I don't know why that happens, but sometimes if they take off a lot [of fluid], you will start cramping real bad. Getting cramps in your legs, arms, side, anywhere. Your hands will cramp real bad...*

As informants continue with hemodialysis treatments, their body awareness heightens, and it alerts them to their vulnerability during hemodialysis. They use this body self-awareness to monitor, make decisions, and direct care in hemodialysis.

> *I didn't know what was going on, but I started putting it together that they had taken off more [fluid] at the time than they should have... I said, 'You need to be mindful of that,' see.*

> *...When you learn your body, when you first start feeling like, I am getting a little clammy here, you immediately tell them... Check my pressure, it is trying to drop. You know, you are going to get this as you go along, different things are going to be happening to your body, and you have to know whether or not it is life-threatening, so you learn.*

Dependence on the Healthcare System and Vascular Access

First, informants realized they are dependent on hemodialysis to live, and second, dependent on a vascular access to have hemodialysis. Subsequently, they realize they are dependent on the healthcare system for dialysis, their vascular access, and other treatments for ESRD. All these dependencies make them vulnerable.

Dependence on a Vascular Access

Informants were very aware of the critical importance of the vascular access and its vulnerability to clotting, trauma, and infection. Informants are dependent on a vascular access, and they poignantly name the lifeline – to receive hemodialysis. "It is your lifeline, so you have to really just protect it." Vascular access is the most vulnerable point in the whole hemodialysis process, as one man metaphorically states:

> *...Truly the blood access IS [loudly] the Achilles' heel of the process. You know without a good functioning access you can't do hemodialysis.*

Mistrust of Providers

Informants quickly realized that they must rely on providers to create the vascular access, provide information about its maintenance and care, and to cannulate or prepare the vascular access for hemodialysis. Some informants had precarious experiences with providers that began with the creation of the vascular access, extended into maintenance and self-care of the vascular access, and continued with cannulation of the vascular access. These experiences can lead to mistrust of providers, and informants may become vigilant and assertive to protect their vascular access.

Mistrust with creation of vascular access. Informants shared perilous experiences they had with providers who did not provide information about what a fistula was, how it would look, and how it would be used with hemodialysis. The lack of and withholding of information often led informants to mistrust providers.

> *I haven't got it quite understood what it [fistula] needs to be like. I have not understood one thing about this. When I went to the surgeon, I asked him, 'What are you doing?' ...Well, he explained he is going to do the stuff with the vein, and put the fistula thing in. I said, 'Can you show me a picture?'* [She speaks with lots of emotion, anger, frustration, and doubt.] *Never got a picture, never got an answer, so I don't exactly know what is even in this arm except he has done the surgery, and he is happy ... I went to the library, and I looked it up on the Internet, what a fistula is supposed to look like, and it looked like a snake or something...*

Several new informants felt betrayed because they did not know how the fistula was used or that big needles would be inserted into the fistula for hemodialysis.

> *...I did not know that they stuck you with needles...this friend of mine... they are now using her fistula, and she says that when they put those needles in that they hurt and her arm did bruise... She says, 'I didn't know they use needles.' I [said], 'Well, I didn't either.' They stick needles in, in the fistula, two of 'em.*

> *...They didn't tell me what it was going to be like. The doctors never explained that they're going to stick some needles into you.*

Mistrust with cannulation of vascular access. Most informants were dependent on professionals to cannulate the fistula or graft, or prepare the catheter for hemodialysis. Hence, this dependency makes the informants vulnerable to the professionals' skills, knowledge, preferences, and actions. Negative experiences with professionals' techniques often led informants to mistrust providers because of fear of temporary or permanent vascular access damage. Consequently, informants were vigilant and assertive to protect their vascular access. The following vignette typifies many informants' experiences and demonstrates their vulnerability with cannulation. This man was determined to self-cannulate to protect his fistula.

> *...When he would do it [insert needles], it was...very uncomfortable because he couldn't see the vein and here he would move, take it out, push*

> *it back in, take it out, push it back in a different way. And you know, that gets uncomfortable after a while...that needle, that big old nail going in and out... He blew up my arm which, what that means is that he would stick the needle in thinking that it's going in the vein, but it's going past the vein, going on the other side of the vein... And then the blood...well, right away when the machine starts up, it's going to push the blood all the way on the other side, and it's going to make a big old bubble on the inside of your skin. Well, they blew up my skin, my veins on this arm so many times I got tired of it, and I would come two days later with a whole blood vessel popped all over my arm... And here they're trying to find the vein because it's all dark now. So that's another reason why...I learned how to stick. I told my wife that...I'm going to have to learn to do this cuz it's up to me. I'm going to have to be the one to see how long I'm going to last and the way I'm going, they're going to kill my arm.*

Maintenance and Self Care Of Vascular Access

Informants must maintain their vascular access lifeline through self-care and be able to recognize when it is functioning and what actions to take when it is not. Body awareness helps informants care for their vascular access through subjective feelings. Maintenance and care for the vascular access begins as soon as a fistula or graft is created or catheter inserted. Informants are dependent on providers to teach them how to care for their vascular access. Several informants discussed receiving little to varying information about how to care for their vascular access.

> *They didn't give me a lot of instructions on the fistula...*

> *I do know that they said...you needed to check it twice a day to see that it was pulsing. Now I don't know what would happen if it's not pulsing.*

Body awareness is part of the informant's vigilance in maintaining and caring for the vascular access. When the vascular access is functioning normally, both during hemodialysis and when not on hemodialysis, the informants feel nothing subjectively at the site of the vascular access.

> *If you feel nothing, then everything is all right...it is the fact that you don't feel anything that you have to keep inspecting it [vascular access] regularly to make sure everything is all right.*

> *The needle stick itself is really the only pain you will feel. If you feel pain when the blood starts flowing [during hemodialysis], something is wrong, and you should stop it, and it should be corrected because that would mean that the needle is in the wrong place, the needle might have gone through the vessel... But under normal dialysis you, will not feel any pain of the blood going out of your body or the blood returning to your body.*

Informants who have had a fistula and/or graft generally identified similar self-care measures for their vascular access. These measures were "keep it clean;" "take the bandages off [after hemodialysis];" "wash it with soap and water;" "no lifting heavy objects – groceries, weights, humans, or pets;" be alert for "pounding sensation, pain, or hardness;" "avoid prolonged bending, restriction, or tightness on the arm" [clothes, jewelry]; "check for a thrill [vibration over the access], thump, or pulse;" and "protect the arm."

A male informant said, "...my biggest fear is the clogging." He knew his vascular access was vulnerable to clotting because of his body position during sleep. He was sad when he shared this information because he missed sleeping with his wife, and he did everything he could and still his fistula clotted "after about a year."

> *They [providers] said when you sleep, keep your arm straight...I sleep part of the time now in a separate bed, in order that I can keep my arm straight...*

Vigilance and assertiveness to protect the vascular access from providers. In addition to protecting the vascular access from everyday events, most informants felt that part of their vascular access maintenance and self-care was to protect their lifeline even when dealing with providers. Informants were vigilant and assertive about this protection both within the hemodialysis setting and in other healthcare settings. Outside the hemodialysis setting, informants protected their vascular access from providers by not allowing venipuncture or a blood pressure cuff on the extremity with the vascular access. They also did not allow blood to be drawn or medications to be administered into their catheters. The following stories illustrate vascular access protection related to mistrust within the hemodialysis setting.

One male informant said:

> *...The tech that was sticking me had a hard time finding it, so he would stick and then start moving the needle around. Well, you know, any time you move a needle around it hurts. And especially those, the needles that you use for dialysis, they're very big. They're like nails. I got tired of them missing the vein so I told, I asked them if I could learn how to stick myself... [The nurse said], 'You show me without making that blood come out of there and stick it as fast as I do, then I'll let you do it.' So I started learning how to stick myself and I haven't missed yet. ...Even when I was in the hospital, I didn't let them stick me. Yeah, I was weak. I stuck me. ...But I told 'em, 'No, I don't allow anybody to stick me.' I don't care who you are. You may be a professional, but I stick myself, and I know my arm. So they...allow me to stick myself, and there's a new nurse that we have now, and she, in the worst way, wants to stick me, and...I just told her, 'NO'* [yelled].

Stigma of a Vascular Access

A vascular access makes informants vulnerable to stigma, which in turn makes them susceptible to rejection and discrimination. There are two types of stigma: internal, how the person feels about his/her vascular access; and external, how other people respond to the vascular access. Although clients must rely on their vascular access, they feel stigmatized from within and from other people. Clients also do not like to look at another client's vascular access.

> *But her arm looks funny to me. The lady that is next to me, it [fistula] looks raw and when he put the needle in. It bleeds a lot, and it is just, I tell you, it is terrible looking, just terrible... I hate to look at my friend in the next chair. Because that whole thing, it looks raw...when we talk...I look the other way.*

Seeing other individuals' vascular accesses probably reinforces the internal stigma clients feel. Clients experience triple stigma: what they feel about themselves when they see others' vascular accesses, and when other people react to their vascular access.

Internal stigma. Internal stigma is an important issue and two male informants discuss how their gender identity is altered because they have a vascular access.

> *It is important. You miss your work, the things you used to do, like guys playing football, you can't do that, a lot of things you just can't do any more, and that is where you feel like they come over and bring in a washer or dryer. You know, I am a man. I am used to getting in there, but I can't do that, and you have to stand back and just watch somebody else do it, and it makes you feel, if you don't have control, you feel like where is your self worth? ...You start thinking about man's work, I can't do this, everybody is cutting wood and I'm here, I have got to cut paper...*

> *...I only barely have enough strength... You see some of these men that can't open...a medicine bottle...how can they not open that medicine bottle? Don't they have the strength? And now I see why because I can't even open up...a medicine bottle. My strength is gone because of all of this [fistula in arm]. So now I have to use these two fingers to undo any bottle...even a Coke bottle. I have to use these two fingers to...and it's very frustrating when you can't, you don't have the strength to open up a bottle. You feel so handicapped, you know, and you have to turn to somebody else [wife] that all your life you've...done for yourself and now you got to turn and ask somebody else to do it for you 'cuz you don't have the strength. That's very frustrating.*

Another man explained why the location of his vascular access was important especially because of the appearance of the vascular access.

> *Yes, he [surgeon] asked me where I wanted it [fistula]. I said up here in my arm* [pointing to upper arm]. *I was afraid he was going to want to come down here [lower arm]. I didn't want it down here, you see it everywhere. See up here your shirt covers all of this, but just think of this, think of all of this down in this part of your arm, where you either have to wear a long sleeve shirt all the time, or it keeps it exposed. ...Appearance...it's VERY* [shouted] *important! Every time I look down, I don't want to see one of my, these faultese things... You know to me, these are things that are different from what the body started out with, and I call them faults. Like a fault in the system, earth. I didn't want to see it every time I raised my arm, because other than that, I forget about it...and in the public, you know I am cognizant of how I look...*

Vascular access makes informants vulnerable to disfigurement, and informants often expressed this as a major reason not to have a fistula or graft.

> *...[The] doctor said to me, 'When are we putting the fistula in your arm?' And I said, 'You are not putting a fistula in my arm'...I have beautiful skin, okay, it is not marred, there are no flaws, and I have seen the arms of the people with fistulas, and I am sorry, maybe it is a vanity thing* [said all of this with emphasis]... *I didn't want my arms looking like, and the guy sitting next to me has these horrible welts on his arms...*

Appearance and body awareness of a vascular access are important to informants. This woman keeps her arms covered when she goes to hemodialysis and while at home. She feels vulnerable and does not want to see the scars.

> *...See how ugly the scar is there. The scars on my arm are huge, HUGE, HUGE* [shouts, makes a distasteful face and motions with arms]. *I am conscious of it and when I go out in public to always wear sleeves on my arms. To me they are not beautiful, they are very unattractive, so I wear sleeves...because when I meet people they say, girl, they have really been cutting on you. I don't want to discuss that with them because it's a painful discussion... When I go to dialysis usually a gown like this or a similar one with sleeves like this, so nobody can just look in there and see the grafts; it is covered up all the time, even when I'm in the house.*

External stigma. When other people see a vascular access, they could have strong physical and verbal responses. These responses reinforce the internal stigma, vulnerability, and body awareness that clients already feel about their vascular access. These feelings can lead to social isolation as a way to protect one's emotional self.

Several informants describe their vulnerability to external stigma.

> *You know, any time a person either has something on their face or something on their...body or they walk a certain way, that's the first thing that they want to know is what's wrong with that person? The thought is not...how are they suffering? The thought is can I catch it? Or do I want to be around it? You know, and that's the first thing that they do...*

> *...His father was a dialysis patient, and people thought he was a drug addict because of the scars on his arm...[from the needles].*
>
> *...Other people that are on dialysis are all worn out from the sticking on top of the arms. It just looks terrible...it looks like if you think of this ten times bigger all on the arm. It gets very, very bulky, very hard, and it...just builds, it builds up. It makes knots all along your skin...where it just looks horrible. Their arms look horrible, look like big spider, spider webs but big old dead skin on top. But her arm looks, there's rows of dead skin on top of here that it just looks horrible. Just, really, she has to have long sleeves because, you know, when you go out into a crowd into a mall, this is the first thing people look at, you know. And if it catches a person's mind...eyes, they're just going to keep looking at it...[and say], 'Wow! Look at that.'*

Discussion

The purpose of the study was to initially focus on the fistula, which the informants discussed and compared to all vascular accesses. Informants realize the importance of having and maintaining a vascular access for hemodialysis. The fistula and graft are abnormal in appearance, painful with cannulation, and limit muscular activity in the extremity where it is placed. They do, however, allow bathing and swimming, which are prohibited activities with a catheter. Advantages of the catheter are that it is painless with hemodialysis and easier to hide. The catheter is usually located in an area normally covered with clothes, even in hot, humid weather. All informants discussed the need to conceal the vascular access because of the stigma it evoked.

Stigma of the vascular access was an important issue for the informants and evoked the greatest emotional responses, especially the appearance of the vascular access. Goffman (1963) identified three types of stigma: physical deformity, character blemish, and tribal phenomena, such as race. When people encounter each other in social situations, they anticipate or expect certain behaviors and/or appearances. When a person has a bodily sign that is unusual or not expected, he or she is placed into a different social category, and the unusual bodily sign is associated with deviant or discreditable behavior. The stigmatized person can have several responses, such as try to change or correct the stigma and /or isolate oneself to avoid uncomfortable social situations. Stigma is usually associated with a feeling of shame (Goffman, 1963).

Findings from this study are consistent with Goffman (1963) in that clients with a vascular access are stigmatized from others, and they reported that people have accused them of taking drugs or having a contagious disease. Clients cannot change or correct the stigma (vascular access); however, they do conceal it and often isolate themselves to avoid uncomfortable social situations. Martin-McDonald and Biernoff (2002) reported that clients have an identifying sign of being on dialysis – stigmata, such as the raised area and scars of a fistula. In this study, clients also described internal stigma because they know the vascular access is abnormal and they disembody their fistula or graft, even though it was part of their body.

Another important finding of this study was that the clients mistrusted providers and felt the vulnerability of temporary or permanent vascular access damage. This is consistent with Curtin and Mapes (2001), who reported that clients carefully presented themselves to providers to prevent harm of their vascular access. Hagren, Pettersen, Severinsson, Lützen, and Clyne (2001; 2005) also reported that clients felt vulnerable when providers had difficulty with cannulation.

This study identified self-care as an essential activity in maintaining the vascular access. Clients identified a number of strategies to maintain the integrity of their vascular access, including self cannulation. Those who self-cannulated said they were less dependent and mistrusting of providers, felt more autonomy and partnering with providers, and had a greater sense of control and power with self-care. Verhallen, Kooistra, and van Jaarsveld (2007) likewise reported that with client self-cannulation, the ease of cannulation improved, pain and the number of missed venipunctures decreased, and clients had less hematomas and scarring and no aneurysm formation, which collectively can decrease disfigurement.

The vascular access is situated in the context of hemodialysis. In addition to the mistrust of providers related to the integrity of the vascular access, other findings of this study were that clients mistrusted the providers and technology of hemodialysis. This was congruent with Calvin (2004) and Curtin and Mapes (2001) who reported that clients also mistrusted providers during hemodialysis and were vigilant and assertive to protect themselves.

Another element that this study illuminated was body awareness of the vascular access and physiological experiences during hemodialysis. Curtin and Mapes (2001) also reported that clients listened to their bodies and sought help if they thought they needed it.

Implications for Research

The clients' mistrust of providers is an important issue and needs to be investigated. Providers can be interviewed to examine their perspectives about hemodialysis, their roles and responsibilities, clients, and vascular access to try and gain an understanding about their behaviors and beliefs that could contribute to clients' mistrust of them. These findings could be compared with the clients' perspectives.

Hopefully, the results of these studies could lead to interventions that would address partnering between providers and clients and the issue of mistrust. Although the sample size and qualitative methodology preclude generalization to the ESRD population on hemodialysis, this study revealed insights into clients' perspectives of the vascular access in the context of hemodialysis.

Implications for Practice

Providers need to recognize and appreciate that clients know their bodies during hemodialysis and when they are not on hemodialysis, and that this body awareness facilitates clients' self-care. It would be beneficial for providers to develop partnerships with clients that address all aspects of hemodialysis, vascular access, and clients' self-care. It is important that providers be aware of the vulnerability of clients and the potential for erosion of trust with them. Providers need to be aware of the feelings clients have about their vascular access, including stigma; encourage them to express these feelings in a caring, non-judgmental environment; and help them problem solve challenges with these feelings.

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Paula Dutka, MSN, RN, CNN, disclosed that she is a consultant for Hoffman-La Roche and Coordinator of Clinical Trials for Roche.

Patricia B. McCarley, MSN, RN, NP, disclosed that she is on the Consultant Presenter Bureau for Amgen, Genzyme, and OrthoBiotech. She is also on the Advisory Board for Amgen, Genzyme, and Roche and is the recipient of unrestricted educational grants from OrthoBiotech and Roche.

Karen C. Robbins, MS, RN, CNN, disclosed that she is on the Speakers' Bureau for Watson Pharma, Inc.

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